# NEUROEPIDEMIOLOGY IN DEVELOPING COUNTRIES

## Manual for Descriptive Studies

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# NEUROEPIDEMIOLOGY IN DEVELOPING COUNTRIES

## Manual for Descriptive Studies

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NIMHANS Publication No. 33

Published in 1994

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Printed at: Eastern Press (Bangalore) Pvt. Ltd., Bangalore.

*Dedicated*

*to*

*the Community*

# Foreword

Neuroepidemiology is a discipline which is still in its infancy in India and other developing countries. There are small nuclei of a few dedicated neurologists, epidemiologists and biostatisticians in India who have been working in this area in the past few decades. One such group is at the National Institute of Mental Health & Neuro Sciences, Bangalore, and I am happy that this group is conducting a workshop on "Neuroepidemiology in Developing countries" for which the present Manual has been prepared.

The Manual provides useful basic information to the neurologists in developing countries who desire to conduct neuroepidemiological surveys on certain practical issues relating to the formulation, planning and conduct of such surveys with limited expert manpower. Guidelines are provided for training the field staff in survey and interview methods. The explanatory notes on the screening questionnaire are rather exhaustive but useful for the neurologists who need to train the field investigators in administering the questionnaire and record the appropriate response from individuals in the community.

It may be mentioned here that the Indian Council of Medical Research Task Force on Clinical Neurosciences had identified Neuroepidemiology as an important thrust area and the NIMHANS was selected as one of the expert centres for conducting neuroepidemiological surveys. In the pilot phase of this project, the NIMHANS Centre developed a screening questionnaire, whose sensitivity and specificity were tested. A manual was also developed for training field workers including medical personnel. With suitable modifications, this questionnaire was used in the main survey initiated in 1993. Thus, this ICMR study has paved the way for the preparation of the present Manual which gives the consolidated information derived from the experience gathered by the ICMR project.

I understand that this is the first attempt of its kind in the area of neuroepidemiology in our country. The authors of this Manual deserve to be congratulated for their dedicated efforts and I hope their contribution will go a long way in stimulating other neurologists to develop the much needed speciality of Neuroepidemiology in other parts of the country.

G.V. Satyavati
Director General
Indian Council of Medical Research
New Delhi.

# Foreword

Epidemiology is concerned with the patterns of disease occurrence in human population and of the factors that influence these patterns. Scientists engaged in Epidemiology are primarily interested in the occurrence of diseases in relation to time, place and person. Descriptive studies are useful in describing the natural history or a spectrum of clinical findings in a group of patients with a particular disease. They may also serve to generate hypothesis for future analytical studies. Epidemiology can be thought of as an integrating eclectic discipline deriving concepts and methods, from other disciplines such as clinical medicine, community medicine, statistics, sociology and biology. Epidemiological studies provide the data which form the basis for developing and evolving preventive programmes and other public health practices.

Epidemiology is now recognised by the clinical investigators as essential in the designing and analysis of research and by the practising physician as an useful tool in patient care. Epidemiological studies of various disorders have been conducted in our country either by individual centres or through multicenter studies. Neuroepidemiology is a relatively recent thinking and not much work has been done in this area in India except in certain isolated centres like Bangalore, Bombay, Delhi and Vellore. There is a need for multi-centered study to understand some of the parameters of neurological conditions which are becoming more and more in our country.

Professor M. Gourie-Devi, Dr. G. Gururaj and Dr. P. Satishchandra of the departments of neurology and epidemiology of this institute have taken a leading role in preparation of this Manual for descriptive studies in neuroepidemiology in developing countries. I am sure this manual will be useful for all the scientists in this field of Neuroepidemiology.

S.M. Channabasavanna
Director
National Institute of Mental Health
and Neuro Sciences, Bangalore.

# Preface

Neuroepidemiology is a newly evolving branch in most of the developing countries including India. Emanating from the pioneering efforts of a few Indian neuroscientists in the last two decades, data on prevalence of neurological disorders from some regions of the country is available. There is an urgent need to generate nationwide data which then can be used for planning specialist services and as well for further indepth research.

While there are a number of excellent and comprehensive text books and monographs dealing with the multifarious facets of the subject of neuroepidemiology, very few, if any, deal with practical issues. Furthermore, the problems in planning and conduct of community based prevalence studies in developing countries are likely to be different from the developed countries, compounded as they are by limited expert manpower, facilities and financial resources. A handy manual addressing stepwise the various issues involved in population based neuroepidemiological studies may go a long way in facilitating the interested neuroscientists to undertake projects.

A number of colleague neurologists had expressed keen interest in the work being done at the National Institute of Mental Health and Neuro Sciences, and a desire to conduct neuroepidemiological surveys in the country. The need for practical guidelines appropriate to the Indian setting was felt to be an essential requirement. The authors, having appreciated the situation, have taken this initiative to consolidate their experience in this manual. A sincere attempt has been made to present the concretised information in a sequential, logical and a reasonably simple style, with emphasis on the practical issues for formulating, planning and conducting neuroepidemiological surveys in the developing countries.

Our efforts will be amply rewarded if the readers find this manual useful.

M. Gourie-Devi
G. Gururaj
P. Satishchandra

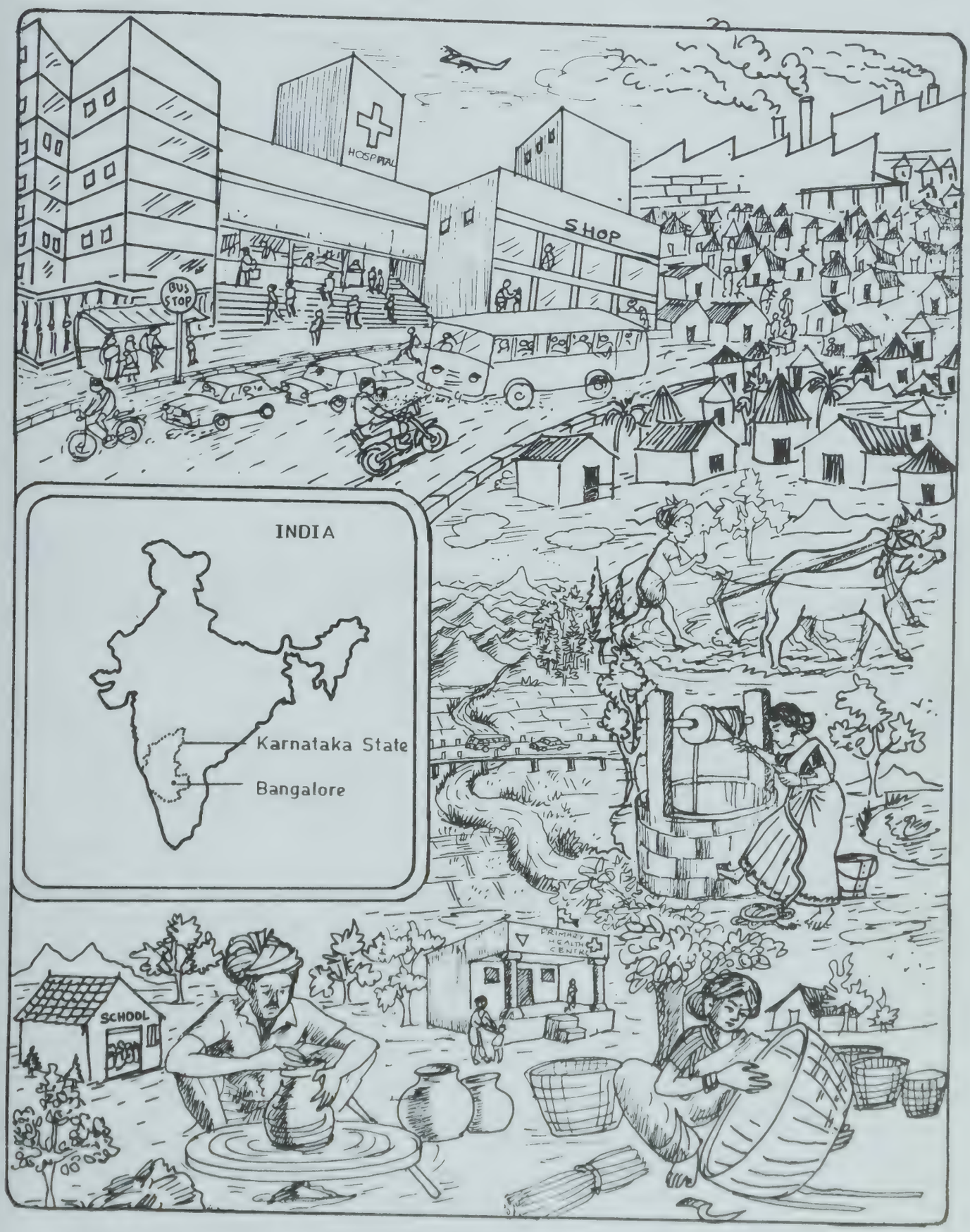
Bangalore, India.

# Acknowledgements

We are deeply indebted to the National Institute of Mental Health and Neuro Sciences, Bangalore; National Academy of Medical Sciences, New Delhi; Indian Council of Medical Research, New Delhi and XIV World Congress of Neurology (India) Trust, Chandigarh, for the generous financial support for organizing the First National Workshop in neuroepidemiology, 1 to 4 September, 1994, and for publication of this manual. Since this manual is an outcome of the research projects on Neuroepidemiology, the authors are also grateful to the National Institute of Mental Health and Neuro Sciences, for the generous grant provided to conduct neuroepidemiological survey in Gouribidanur (Karnataka State) (1982-1984) and to Indian Council of Medical Research for the Pilot Survey (1989-90) and Main Survey (1993-94) to determine the prevalence of neurological disorders in the urban and rural population of Bangalore. We are deeply indebted to Dr. G.N. Narayana Reddy, Former Director and Dr. S.M. Channabasavanna, Director and Professor of Psychiatry, NIMHANS, for constant encouragement and continued support to the neuroepidemiology programme at this institute. We also owe special thanks to Dr. G.V. Satyavati, Director General, Indian Council of Medical Research and to Dr. S.M. Channabasavanna for the foreword to this manual.

We are especially grateful to D.K. Subbakrishna, for advice in planning the Bangalore Urban-Rural Neuroepidemiological (BURN) study and for helpful suggestions in preparation of this manual. We are also grateful to Maj. R. Varadarajulu, for providing valuable support to the programme. We express our deep sense of appreciation to our colleagues V.N. Rao and P. Rajaram, in the Gouribidanur project and J. Ahamed, K. Venkatesh, V.S. Kargudri, J.R. Babu Reddy, Y.N. Rajasekhar, R. Muniyappa, S.D. Manegar, L. Vijaya, K.P. Puttaswamaiah, T.G. Srinivas and Ananda, who were associated at various stages in the BURN study. We appreciate the assistance of N. Gopalakrishna and H.N. Nagaraj in preparation of the manuscript and S. Sripathi and V. Manja for the art work.

M. Gourie-Devi
G. Gururaj
P. Satishchandra


HOSPITAL
SHOP
BUS STOP
INDIA
Karnataka State
Bangalore
SCHOOL
PRIMARY HEALTH CENTRE

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## Section 1

# Introduction

Many developing countries, although still besotted with communicable diseases and malnutrition, are passing through a gradual and progressive transformation in the health scenario as a result of improvement in health care services and advances in medical technology in preventive and curative aspects. A speciality like neurology, earlier relegated to the periphery, is now gaining importance due to increased awareness, development of newer diagnostic and therapeutic modalities. At this juncture the time is ripe enough to rationalize expert services and generate manpower based on judicious and pragmatic forward planning. Epidemiological approaches have been meaningfully adopted in successful structuring of health services for a variety of diseases world over. Therefore, a similar strategy can be applied for management and control of neurological disorders.

Information on the magnitude of neurological disorders in the community is vital for need-based planning of neurological services at local, regional, national and global levels. Although information on epidemiological aspects of neurological disorders in the developed countries is available, since geographic, ethnic, cultural and social influences determine disease pattern and prevalence in the population, it is vital to conduct similar studies in developing countries for undertaking interventional measures (Gourie-Devi 1987). Epidemiological studies based on hospital population, geographic isolates, focused groups provide valuable information of disease pattern but do not reflect the prevalence nor the changing trends of diseases over a period of time in the community. Population based neuroepidemiological studies provide useful data for estimating the magnitude of neurological disorders, for strategic planning and organization of neurological services as well as projecting the manpower requirements. Descriptive neuroepidemiological studies primarily focus upon prevalence and for incidence of a disease(s) and sociodemographic determinants (Gourie-Devi *et al.* 1987; Gururaj and Satishchandra 1992a; Gururaj *et al.* 1992b). Analytical epidemiological studies (case control and cohort studies) provide the possible aetiological basis of neurological diseases (Gourie-Devi *et al.* 1993; Satishchandra *et al.* 1988). Meticulously designed intervention trials provide scope for

development of new therapeutic modalities which subsequently lead to intervention and preventive programmes. In view of these implications it is vital to carefully design and plan neuroepidemiological studies (Kurtzke 1984 and 1986).

The neuroepidemiological studies in 70's and 80's in Bangalore (Gourie-Devi *et al.* 1987), Bombay (Bharucha *et al.* 1987), Delhi (Kapoor *et al.* 1990) and Vellore (Abraham *et al.* 1970; Mathai 1969), the result of pioneering efforts of researchers, formed the foundation and provided stimulus for emergence of the discipline of neuroepidemiology in India leading to studies in other regions of the country (Razdan *et al.* 1994). These studies have successfully demonstrated the feasibility of conducting population based studies by a two-stage method involving preliminary screening for neurological disorders by training nonprofessionals and subsequent examination and diagnosis by a neurologist. A similar strategy has also been recommended for developing countries (Schoenberg 1982). While the efforts are laudable, the problems encountered in comparison of data across regions were chiefly due to the use of varied screening questionnaires and lack fo uniform standardized definitions for disease diagnosis and classification.

World Health Organization neurosciences programme having recognized such problems in epidemiological surveys done world wide, devised a questionnaire and simple clinical tests to be carried out by health workers followed by assessment by neurologists (WHO 1981). This protocol was adopted in the surveys conducted in China (Li *et al.* 1985), Ecuador (Cruz *et al.* 1985), India (Bharucha *et al.* 1987), Nigeria (Osuntokun *et al.* 1982), Sicily (Meneghini *et al.* 1991) and Tunisia (Romdhane *et al.* 1993). In our earlier survey conducted at Gouribidanur, Karnataka State in 1982, the WHO protocol was modified to include a wider spectrum of neurological disorders and clinical examination by health workers had to be omitted due to nonacceptance by the community (Gourie-Devi *et al.* 1987 and 1988).

The scientific advisory group on neurological sciences constituted by the Indian Council of Medical Research in 1986 had identified neuroepidemiology as a thrust area of research. Under this programme, NIMHANS had been identified as one of the centres for conducting neuroepidemiological survey. In the pilot phase of the project in 1989-90, a screening questionnaire was developed and sensitivity and specificity assessed. A manual for training of field workers and medical personnel along with definition of neurological disorders and diagnostic index were developed and adopted during the pilot phase. Certain problems encountered in the screening questionnaire were overcome by suitable modification. This final version was used in the main survey for urban and rural population from January 1993 and found to be satisfactory.

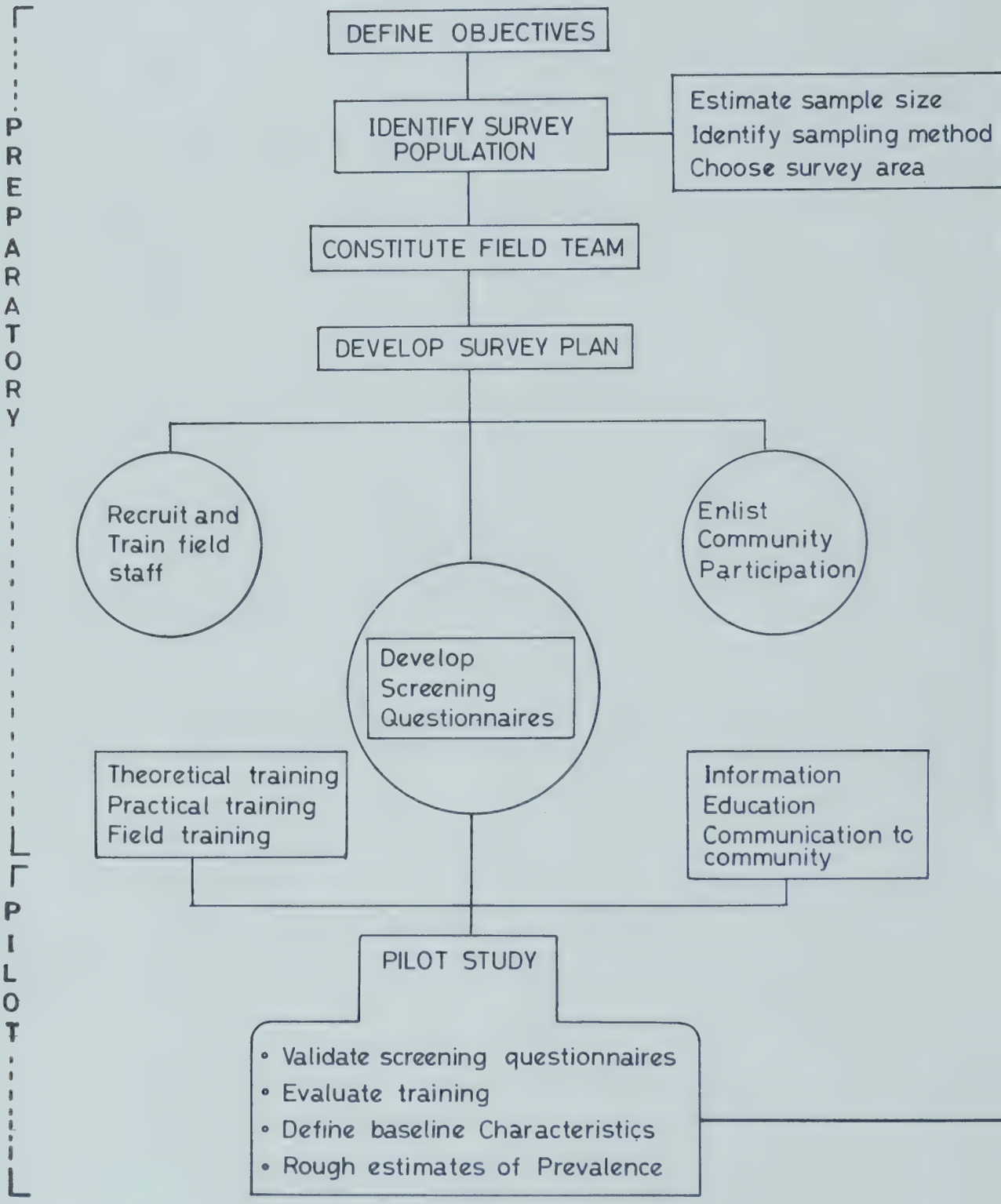
This present manual is a compendium of our experience purporting to provide certain important theoretical concepts underlying neuroepidemiological surveys and focus on methodological issues and practical guidelines, for descriptive neuroepidemiological survey. (For further information on derscriptive neuroepidemiology including surveillance, analytical and experimental neuroepidemiology, the reader is advised to refer to many published books on the subject (Section 11b). Selection of population for survey, screening questionnaires, training of field staff, pilot and main survey, method of data collection, monitoring of work schedules, data analysis and utilisation are salient issues discussed in this manual. In the appendix the proformas and other relevant materials used in our Bangalore – Urban – Rural – Neuroepidemiological (BURN) study, glossary of commonly used epidemiological and statistical terms and selected bibliography are included for ready reference.

# SCOPE OF NEUROEPIDEMIOLOGY

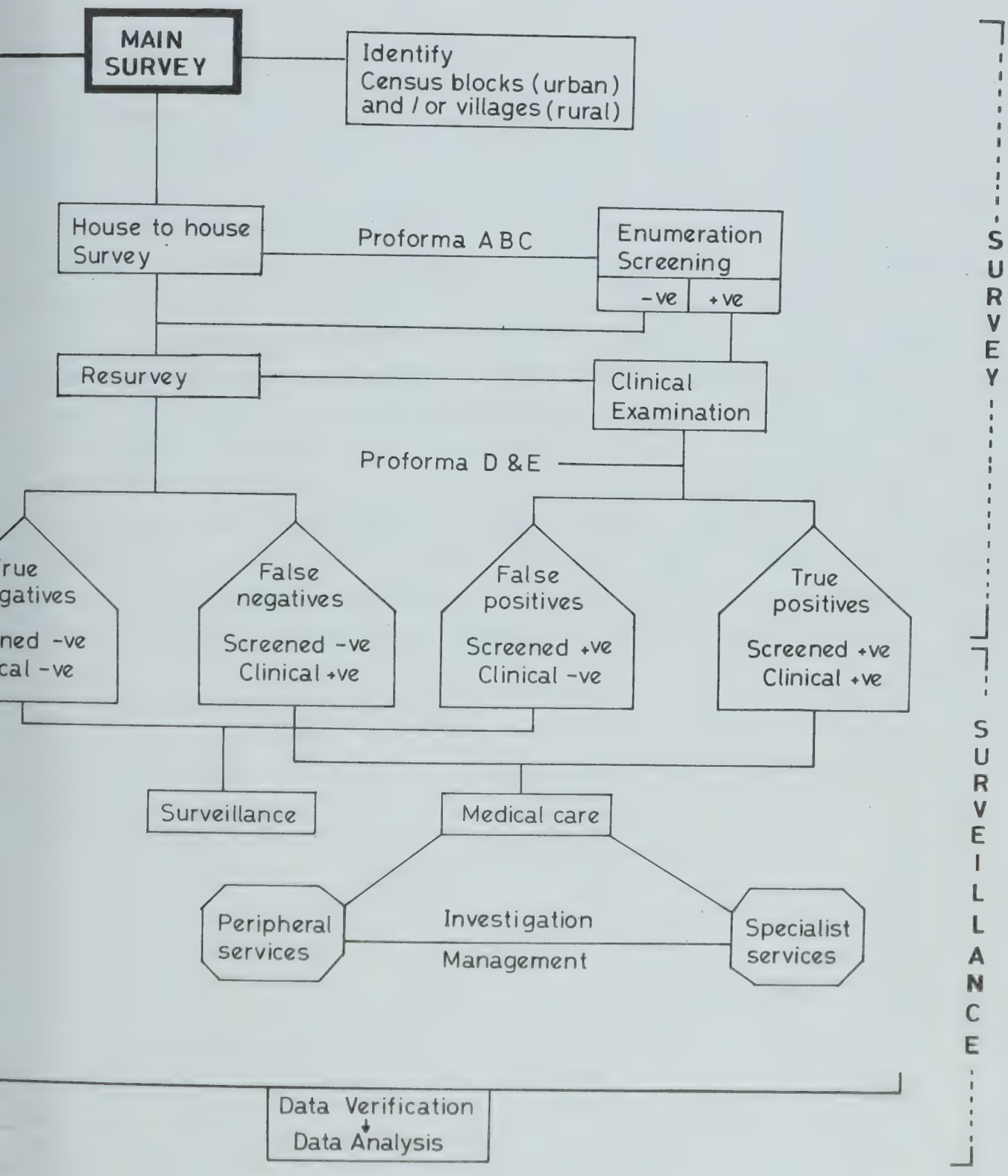
The ultimate aim of neuroepidemiology is to reduce neurological problems and its consequences in the community by:

1. Studying variation in the occurrence and distribution of neurological diseases in different communities.
2. Establishing a community diagnosis of the presence, nature and distribution of neurological disorders through morbidity and mortality rates along with identifying high risk population.
3. Identifying causes of neurological diseases by defining various geographic, demographic, genetic, environmental and social factors.
4. Estimating individual risks and chances toward disease occurrence in general or specified segments of population.
5. Identifying and describing various syndromes in the community.
6. Detecting clinical and subclinical forms of neurological disorders in communities for early diagnosis through screening mechanisms.
7. Studying knowledge, attitudes, beliefs and practices of communities towards neurological problems and to develop intervention programmes.
8. Investigating epidemics of neurological problems and to evolve appropriate intervention programmes.
9. Completing natural history of diseases affecting nervous system.
10. Developing strategies for planning, organizing, implementing, integrating and evaluating services in communities.

# NEUROEPIDEMIOLOGICAL



# SURVEY


MAIN SURVEY
Identify
Census blocks (urban)
and / or villages (rural)
House to house Survey
Proforma A B C
Enumeration Screening
-ve
+ve
Resurvey
Clinical Examination
Proforma D & E
rue
gatives
ned -ve
cal -ve
False negatives
Screened -ve
Clinical +ve
False positives
Screened +ve
Clinical -ve
True positives
Screened +ve
Clinical +ve
Surveillance
Medical care
Peripheral services
Investigation
Management
Specialist services
Data Verification
Data Analysis
SURVEY
SURVEILLANCE

## Section 2

# Survey: Aims

---

A survey is a study or investigation, the purpose of which is to obtain more information on specific problem(s) within a community. A clear perspective of the situation between patients seeking help from a speciality centre and those in the community who may or may not be availing services is obtained from survey. This method incidentally is also a tool for the provision of better health care services to the people. The fundamental issue is to clearly formulate the questions to be investigated and to explicitly delineate the aims and objectives. It is also necessary to define the type and depth of information aimed to be collected, taking into cognizance the already existing data of the population selected for survey. Clearly defined objectives with focused questions yield meaningful results without dissipating manpower and financial resources. Although these are general principles in research they have a special significance in the field of neuroepidemiology, since the available manpower and financial resources are limited.

## Section 3

# Selection of the Study Population

Ideally, prevalence of diseases should be determined by survey of the entire population. The constraints of finance, manpower and time required for obtaining data are the obvious limiting factors. Therefore, there is a need for selecting a representative sample of optimum size, which should closely reflect the community in all aspects.

The choice of population depends on the objectives of the proposed study. e.g., for studies aimed at determining prevalence of a disease or factors influencing its occurrence (e.g., socio-demographic, environmental and other risk factors), a representative sample of the population should be chosen, so that the results obtained can be extrapolated to a larger section of the population. On the other hand, epidemiological surveys aimed at determining the disease prevalence and pattern in specific groups of population, such as ethnic groups (Parsis, tribals), specific age groups (children, elderly women), at risk population (industrial workers, miners, people residing near high exposure areas) and geographic isolates, (Himalayan belt for iodine deficiency, sickle cell anemia in tribals, amyotrophic lateral sclerosis in Guam), are focused on well defined target population groups.

### 3.1 Representative sample

The term representative implies that the sample resembles the population in demographic and socio-cultural aspects and health status. While selecting the representative sample, caution has to be exercised to include only stable population, thereby meaning that the migration in and out of the area is minimum. The stability of the population is an important consideration for obtaining reliable rates and for conducting longitudinal studies. In our BURN study, subjects residing in the area for more than six months were included with the exception of new born babies under the age of six months.

The situation in urban and rural areas is significantly different with respect to migration. In major cities, the migrant population comprises of construction and quarry workers, people involved in seasonal business and on temporary employment as well as students who also constitute

a significant proportion. In the rural areas, seasonal migration of agricultural labourers occurs depending on the local conditions of monsoon, irrigation and type of agricultural crops grown. Pavement dwellers, a phenomenon of rapid urbanization, pose special problems in urban surveys. Depending on the period of stay and design of the study, decision should be made to include the latter group.

The next important consideration is that the sample should originate from the entire geographic limits of the study area within the clearly defined boundaries.

### 3.2 Sample size

The determination of sample size is based on the frequency with which a disease occurs in the population. The lower the frequency of the disease, the larger should be the sample size for reliable results. A smaller sample size may be accepted for diseases with high prevalence rates. If sample size is too small it may not be possible to make sufficiently precise and confident generalizations about the population or to obtain statistical significance when associations are tested. On the other hand, it is wasteful to study more subjects than required. If sample size is too large, even small differences will be statistically significant and hence there may be a tendency to give importance to trivial differences. In order to determine the sample size the investigator has to decide, how precise the estimate has to be, the desired confidence level and acceptable margin of error and risk. For detecting the differences between groups a prior decision has to be made about the magnitude of the difference, desired level of significance and the power of the tests of significance. The practical problems like nonavailability of a large sample or insufficiency of resources should be taken note of and a balance must be struck between the cost and usefulness of the sample. The larger the sample the lesser will be the sampling variation.

Usually if the proportion of cases in the population is 'p', the sample size required is estimated using the relationship:

$$n = z_\alpha^2 \, p(1\text{-}p)/d^2$$

where $z_\alpha$ is taken from normal tables to set the type 1 error, and 'd' is the difference the investigator is prepared to afford between the actual value in the population and the sample value. $z_\alpha$ is usually fixed at 5% equal to 1.96 from normal tables. Thus, by using this method for a known variability and tolerance, one can compute the sample size for the study.

Our earlier Gouribidanur (Karnataka State) study (Gourie-Devi *et al.* 1987) showed a prevalence rate of 14 per 1000 population. Based on this figure the optimum sample size would be:

$$n = \frac{(1.96)^2 \times 0.014\ (1-0.014)}{(0.001)^2}$$

with the value of 'd' taken as 0.001, the sample size required would be approximately 50,000.

There are a number of methods for calculating sample size, information on which can be obtained from statistical text books, standard manuals and computer programs (see bibliography)

### 3.3 Sampling methods

The main purpose of taking samples is generally to estimate certain population parameters by studying a smaller representative sample. The decision to sample is usually taken because the investigator may not have enough resources to study the entire population. The procedure of sampling may make better use of available resources because of the restricted number of individuals to be studied. And, it is also possible to investigate each of them more fully by making greater efforts to obtain information from each individual. Under certain conditions it is possible to apply the results obtained by a sample to the population from which it has been drawn with a specified degree of precision. Statistical techniques can be made use of to study with what precision and confidence, inferences can be made.

The sample chosen in a haphazard fashion is unlikely to be a representative one and is called convenient sampling. The method of probability sampling in which each individual in the population has a known probability of being selected is usually used in most of the studies. Sometimes judgement sampling is made use of, the obvious disadvantage being that the persons chosen may not be representative of the entire population.

Before taking any sample it is usual to make a list of all the units in the population. Such a list is known as a sampling frame. The major sampling methods which can be adopted are simple random sample, stratified random sample, systematic sample and cluster sample (see Section 12 for definitions).

In the BURN study, a 2-stage stratified random sampling method was used to obtain a sample of 50,000 each, in urban and rural areas (Fig. 1).

The city of Bangalore has a population of 40,86,456 (1991 census) distributed in 87 census divisions. In the first stage, 10% (9) of these census divisions were selected by a computer generated random number (can also be chosen from the table of random numbers). Each division

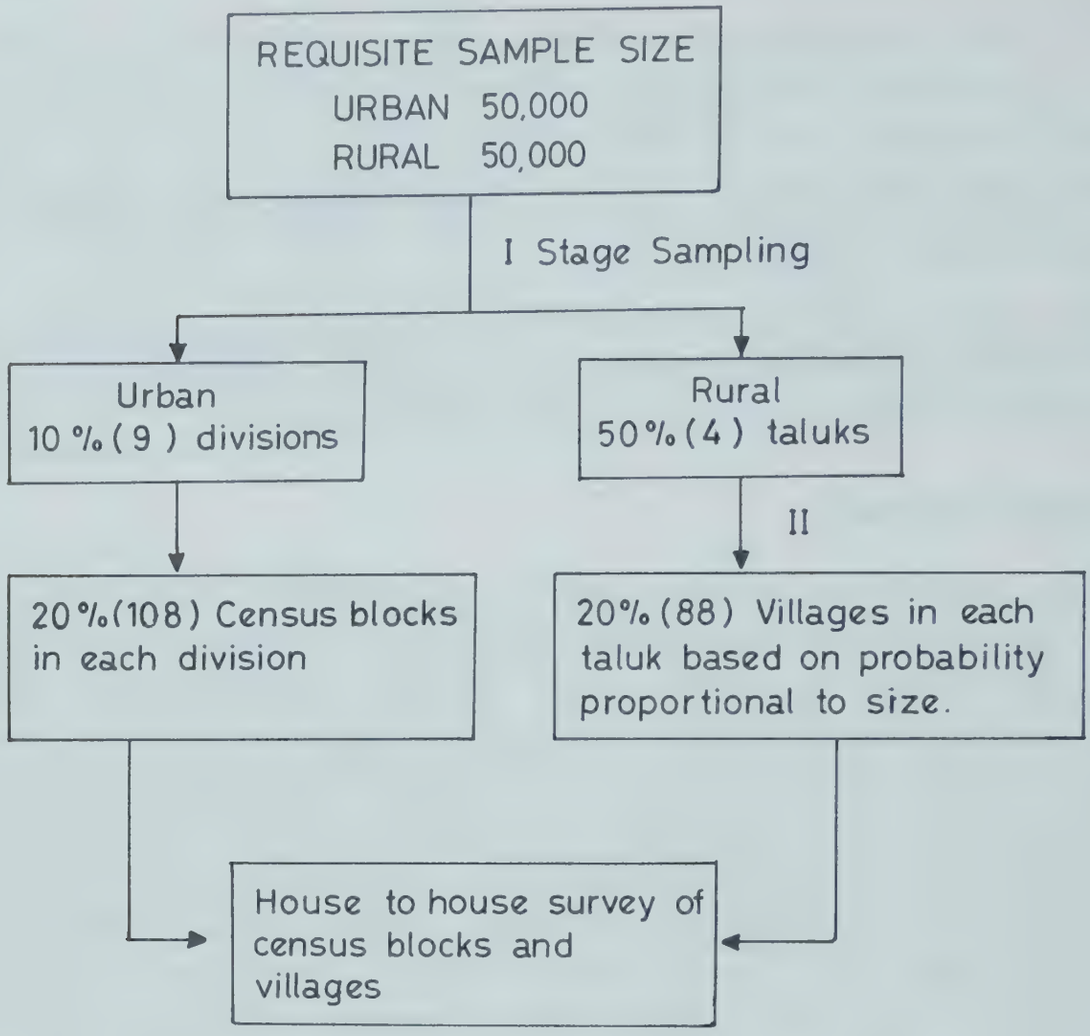

REQUISITE SAMPLE SIZE
URBAN 50,000
RURAL 50,000
I Stage Sampling
Urban
10 % ( 9 ) divisions
Rural
50 % ( 4 ) taluks
II
20 %(108) Census blocks in each division
20% (88) Villages in each taluk based on probability proportional to size.
House to house survey of census blocks and villages

Fig. 1. Neuroepidemiological survey: Sampling method. Used in Bangalore Urban Rural Study (BURN) 1993-1994.

consists of several "census enumeration blocks". The number varies from division to division depending on the population size. In the second stage, from each of the 9 divisions, 20% of the "enumeration blocks" were chosen by computer generated random numbers. Finally, the enumeration blocks to be surveyed were 108. It is clear that there was no selection bias for any particular area of Bangalore to be included in the survey and every "division" or "enumeration block" had an equal chance of being included.

Bangalore rural district has a total population of 13,69,908 spread over eight taluks. The sample of 50,000 was selected based on the principle of probability proportional to size by a two stage sampling method. This sampling method was based on the proportion of population in each of the taluks with respect to the entire population of rural district. In the first stage four of the eight taluks of Bangalore rural district were selected randomly. The total population of these four taluks was 6,18,234. The proportion of population in each of these taluks with respect to the total population of these four taluks was computed. Subsequently the same proportion was used to select the sample size of 50,000. Thus, 19%, 28%, 28% and 25% of study sample was selected from each of the four taluks of Devanahalli (9,550), Doddaballapur

(14,000), Magadi (14,000), and Ramanagaram (12,450), respectively, which amounted to 50,000 population. In order to select the requisite study sample, the villages in these four taluks were stratified as small and big based on the population size of $< 1000$ and $> 1000$ respectively. A total of 84 small and 8 big villages were selected for the survey.

After a sample has been chosen, it is possible that some of the selected subjects cannot be investigated due to refusal, death, migration or nonavailability due to a variety of other reasons. Usually it is tempting to replace such subjects with other randomly selected subjects. Though this is an acceptable procedure it should be noted that if the omissions produced sample bias, substitution will not remove this bias, net result being a large biased sample instead of a small biased sample. On the other hand, it may be worthwhile to study the omissions if they are large in terms of their demographic and other characteristics and the relevance of this difference if any, to the study findings.

### 3.4 Survey site

The choice of area of survey would depend to a large extent on the objective of the study. Well defined geographical boundaries, easy approachability and availability of basic health care services are some of the important prerequisites while selecting the survey site. However, studies focusing on special problems need not necessarily adhere to the guidelines as in the investigation of an epidemic or study of tribal people living in hilly terrains.

The survey area has to be initially identified using the census notional and layout maps or through information from other sources. It is essential to demarcate the boundaries and identify important land marks. Based on the notional maps the actual boundaries and roads/streets are identified by visit to the site keeping in view that alterations are likely to occur over a period of time. The land marks indicated in the maps should be reidentified along with the location of houses using the layout maps. It is important to note places of public utility like police station, post office, schools, places of worship, health dispensary, business centres, etc, for purpose of easy identification and location of household for future survey or follow up studies. Difficulties faced in identification of boundaries and land marks, can be overcome by seeking assistance of postman, police staff, school teachers, shopkeepers and local administrators. If major changes had occurred in the locality after the preparation of notional and layout maps from previous surveys, fresh maps need to be drawn by the research team during the survey (Figures 2 and 3).

राज्य/संघ राज्य क्षेत्र का नाम
Name of State/Union Territory Karnataka

जिले का नाम Bangalore Urban
Name of District Bangalore Urban कोड सं० Code No. 01

तहसील/तालुका/पुलिस थाना/विकास खंड/सर्किल आदि का नाम
Name of Tehsil/Taluka/P.S./Dev. Block/Circle etc. कोड सं० Code No. --

ग्राम/नगर का नाम
Name of Village/Town Bangalore कोड सं० Code No. I

वार्ड/मोहल्ला/हैमलेट का नाम या नम्बर
Name or No. of Ward/Mohalla/Hamlet Bhatiagar कोड सं० Code No. 11/82

प्रगणक के ब्लाक का नम्बर
Enumerator's Block No. 33

विकास खंड का नाम
Name of Dev Block ____ कोड सं० Code No. ____

संकेत :
REFERENCES

ब्लाक की सीमा
Block Boundary

पक्का मकान (नम्बर सहित)
Pucca House (with No.)
निवासीय Residential 12
गैर निवासीय Non-residential

कच्चा मकान (नम्बर सहित)
Kutcha House (with No.)
निवासीय Residential 5
गैर निवासीय Non-residential 16

पक्की सड़क Pucca Road
कच्ची सड़क Kutcha Road
आम रास्ता Common way
रेलवे लाइन Railway Line (i) बड़ी लाइन Broad Gauge (ii) छोटी लाइन Meter Gauge
नदी River
नहर Canal
तालाब Pond
कुआं, पानी का नल Well, Water Tap
मन्दिर, मस्जिद, चर्च आदि Temple, Mosque, Church etc.
स्कूल, औषधालय, पंचायत घर, डाकघर आदि S D P PO
School, Dispensary, Panchayat Ghar, Post Office etc.

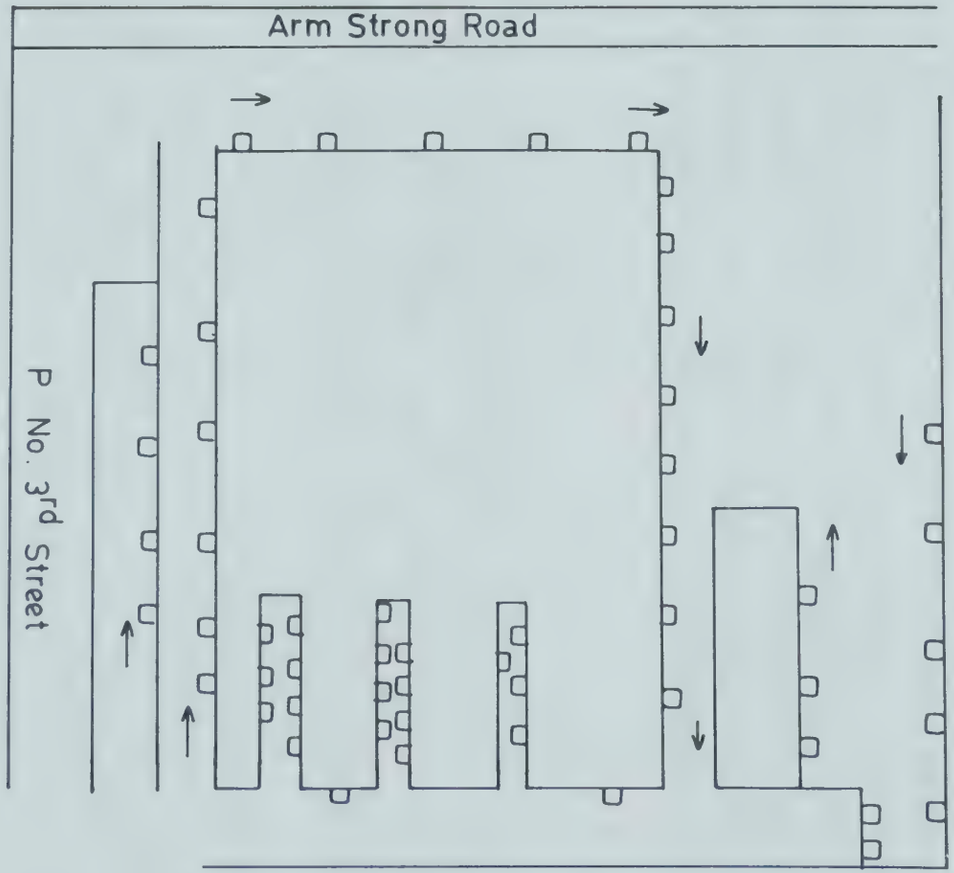
टिप्पणी NOTE : (i) कृपया ब्लाक में मुख्य सड़कों, गलियों और मोहल्लों आदि के नाम लिखें। मन्दिर, स्कूल, औषधालय, पंचायत घर, डाकघर आदि संस्थाओं के नाम भी लिखें।
Please write the names of prominent roads, streets and Mohallas etc. in the Block. Also indicate the names of institutions like Temples, Schools, Dispensaries, Panchayat Ghars, Post Offices etc.

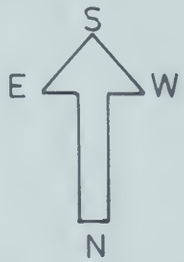
(ii) कृपया उस दिशा को तीर के चिह्न से दिखाइए जिस ओर से ब्लाक में नम्बर दिये गए हैं।
Please indicate by an arrow the direction in which the numbering has been done in the Block.

प्रगणक का नाम
Name of Enumerator [signature]

हस्ताक्षर
Signature ____

सुपरवाइजर के हस्ताक्षर
Signature of Supervisor [signature]



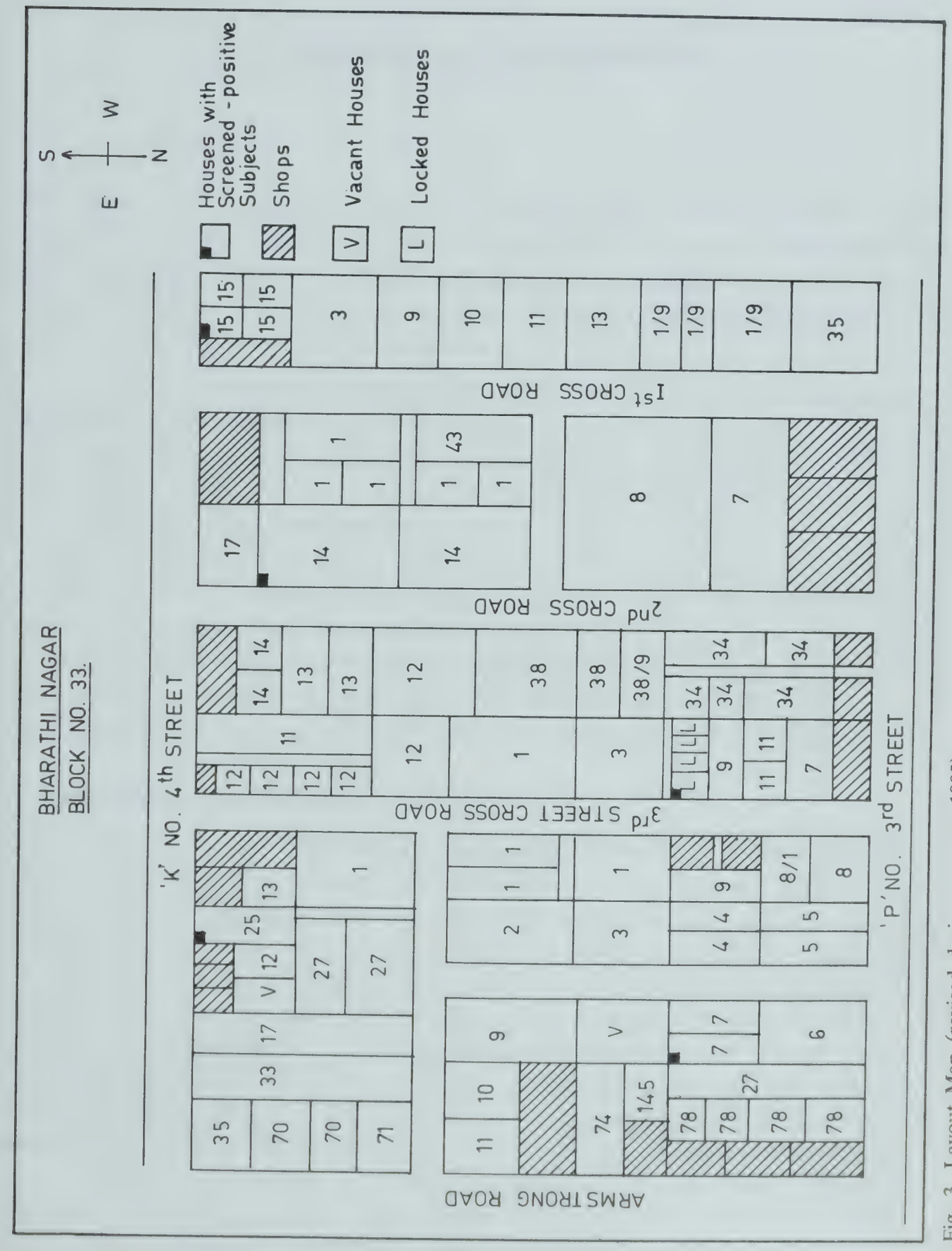



Fig. 3. Layout Map (revised during survey - 1993)

## Section 4

# Screening Instruments

The aim of screening is to detect individuals with symptoms of the disease under investigation. Several methods like mass screening, high risk screening and multiphasic screening are available and the choice of the method depends upon the disease characteristics, screening instruments and available resources.

In order to identify relatively uncommon disorders like neurological disorders in the community, screening of a large population is necessary. This can be achieved either by 'one-stage' or 'two-stage' method. In the former mode, a neurologist performs screening which may consist of a questionnaire administration and a clinical examination. To survey a large population, adequate expert manpower would then be necessary. In developing countries with large population and with limited trained expert manpower and financial resources, a 'two-stage' survey has been recommended by World Health Organization (Schoenberg 1982). In the first phase, screening is done by field investigators (health workers, lay investigators) and the screened positives are then examined by neurologist.

### 4.1 Screening questionnaire

The objective of the screening questionnaire is to collect sociodemographic data and information related to the presence or absence of the disease under survey. A screening questionnaire has to be simple, easy to administer, inexpensive and cause minimal discomfort to the community. In addition, the results emanating must be valid, reliable and reproducible (Hennekens and Buring 1987). For neuroepidemiological survey, well tested questionnaire for determination of prevalence of some common neurological disorders, has been developed by World Health Organization, Neurosciences Division. To cover a wider spectrum of neurological disorders, we had developed a protocol which was used successfully in the Gouribidanur study in 1982 (Gourie-Devi *et al.* 1987). The same protocol was used in the pilot phase of Bangalore – Urban – Rural – Neuroepidemiology (BURN) study in 1989-90 supported by Indian Council of Medical Research. Few modifications were incorporated and the final version which is currently being used for the main phase survey

of BURN is included in appendix ii and iii. For conducting epidemiologic surveys on specific disorders like epilepsy, stroke, etc. elaborate questionnaires aimed at obtaining information about the disorders have been developed (Sander and Shorvon 1987, Weddell 1980).

The three questionnaires used in the BURN study elicit information on sociodemographic characteristics (proforma A), presence of neurological disorders in individuals of 7 years and above (Proforma B) and children under 7 years of age (Proforma C) (See appendix i, ii and iii). The sociodemographic details include identification and location of household, family composition and socioeconomic status. The questions to elicit information regarding the symptoms can be addressed to the head of the household/surrogate respondent or individual family member. Obviously for children who cannot respond, information has to be obtained from parents, preferably the mother. The information about the members of the family can be conveniently elicited from the head of the household or surrogate respondent. Particular attention to educational status and occupation is necessary as it may have relevance to some of the neurological disorders. Many classifications are available and the most suitable one can be adopted. The method used in BURN study is shown in appendix vi. Screening questionnaires, one for subjects of 7 years of age and above and second for those below 7 years, used in our study are in conformity with the World Health Organization research protocol (WHO 1981). The basis of this categorization is that recall about motor and mental developmental milestones as well as seizure disorders specific to infancy and childhood would be possible in smaller children rather than older children, adolescents and adults. The entire screening questionnaire including the explanation of each symptoms has to be translated into the commonly used local language(s) and back translated to ensure accurate reproduction of contents.

The questions have to be clearly asked in the language best known to the respondent to elicit the response. If the question is not understood than further explanation as provided in the section under each question has to be offered. If the respondent is not aware about the details of a particular member of the family, the interviewer should interrogate the concerned member.

The various items with explanatory notes in Proformas A, B and C used in BURN study are provided below:

### *a. Proforma A – A Sociodemographic details*

1. *Serial No.:* This number should be filled at the coordinating nodal cell and not by the field investigators at the site, so as to avoid duplicate numbers.

2. *Area Code:* It is prefereable to use the census code for the area under survey. Retrieval of data, comparison between different areas and formal hypothesis for variation in disease occurrence would be possible. Place and date of survey, name of the block/village and house number should be accurately entered.

3. *Name of the head of household and address:* The full name of the head of the household and the full postal address along with telephone number if available has to be entered. Should there be any clarification in future, necessitating repeat interview of head of the household, it would be easy to trace the correct address and person.

4. *Name of the respondent and relation to head of the household:* If the head of the household is not available at the time of the interview, the surrogate respondent has to be interviewed. The name of this respondent and the relation to the head of the household has to be entered.

5. *Religion:* It is important to obtain the information of religion since there is a predilection of certain religious groups to specific neurological disorders.

6. *Family size and income:* The income and the number of members in the family reflects the socioeconomic status. The income entered should include revenues from all sources and from all the family members.

7. *Period of stay in the locality/village:* A minimum period of stay in the locality has to be fixed before commencing the survey. To avoid inclusion of migrant population and obtain data only on stable population a six month period residence is a resonable limit for neuroepidemiological survey. However for investigation of epidemics, the period can be suitably shortened.

8. *Family composition:* Name, age, sex and relationship to the head of the household have to be entered. Education and occupational status are important determinants of health. There are several methods of classification (ICMR, International Labour Organization, census classification, International Association of Occupational Health and others). The methods adopted in BURN study, are depicted in appendix vi.

9. *Age:* Obtaining the data of birth would be an accurate way of determining the age. However, in a significant proportion of population, the exact date of birth is unknown and age has to be fixed in relation to some major events in the family, in the local community or national events. Among the elderly, the age has to be determined in an indirect manner by ascertaining the age of the children or grand-children.

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10. *Symptoms:* The members with symptoms should be identified and coded (1. Present 2. Absent). This information is useful for monitoring of the work, completion of relevant proformas and clinical examination of the screened positive subjects.

### *b. Proforma B – Screening questionnaire for individuals 7 years and above*

1. *Loss of consciousness:* Loss of consciousness means that a person may suddenly fall down and does not respond to questions. Such episodes may or may not be associated with vigorous movement of hands and legs. The duration of the attack is for a few minutes but sometimes recurrent attacks may occur in a quick successive manner lasting for few hours to days.
2. *Sudden episodes of loss of contact with the surroundings:* The person does not appropriately respond to question or command during the episode, but may continue the activities which were being done. Usually the person does not fall down. The duration of such episode is brief lasting for few minutes. Prolonged attacks may also occur.
3. *Shaking of head, arms or legs which could not be controlled:* Shaking of head, arms, or legs (either one or both) which cannot be controlled may be mild or very severe. The movements may either be temporary or continuously present. The person may be fully alert and aware of the movements or may be unconscious.
4. *Is the speech abnormal?* There may be difficulty in speaking clearly, or the person may not be able to speak at all or speech may be slow.
5. *Has the face ever been paralysed with deviation of mouth to one side?* The paralysis of the face usually of one half, may be of sudden onset or gradually progressive. While laughing, the mouth may deviate to one side. While drinking water, drops may trickle from the sides of the mouth.
6. *Have the arms or legs ever been paralysed?* Difficulty in moving the arms or legs may occur suddenly or gradually. Assistance may be required for carrying out routine daily activities like bathing, dressing, eating etc.
7. *Is there any difficulty in walking properly (to exclude individuals with pain or swelling of joints of lower limbs)?* There may be difficulty in walking fast or while walking the person may sway or fall down on repeated occasions. Care must be taken to exclude those individuals with difficulty in walking due to pain or swelling of joints.
8. *Has the sensation over the face, arms and legs ever been lost or abnormal?* Feeling hot or cold water or objects, or pain after a

thorn prick or accidental cut may be less or absent. Presence of severe burning sensations or 'ants crawling' sensation may be felt.

9. *Has the memory deteriorated within the last five years? (Applicable to subjects above 30 years of age).* The deterioration in memory may be:
   a) Difficulty in remembering names of family members or close friends
   b) Mistakes in simple calculations e.g. getting back the correct amount of money after buying some articles in the market.
   c) Important events in the individual's life or family members (e.g. birth, marriage and death) are forgotten.

10. *Has drooping of eye lids ever occurred? (a) Temporary for few hours or (b) permanent.* One or both eyes may close either partly or completely. The person will not be able to open the eyes fully on his own without using the fingers.

11. *Episodes of severe pain in the face* Severe excruciating pain in one or both halves of the face occurring spontaneously or precipitated by washing face, eating or drinking. These episodes may occur intermittently or may be continuously present.

12. *Headache – if present*
   a) is it unilateral
   b) is it associated with circles or flashes of light
   c) is it associated with vomiting.

***c. Proforma C – Screening questionnaire for individuals below 7 years of age***

The explanatory notes for questions 1, 4, 5, 6 and 7, are similar to questions 1, 3, 5, 6, and 10 respectively of Proforma B.

2. *Does the child have episodes of blank look and unawareness of surroundings?* The child may suddenly stop whatever activity that is being carried out and may have a blank or "confused" look on the face. The child may not respond to calling by name or any command. May even perform some activities without being aware of the act. These episodes may last for a few seconds to few minutes.

3. *Did the child ever have fever followed by convulsions (for children under 6 years of age only)?* Fever due to any cause may be associated with a fit, characterized by loss of consciousness with or without movements of hands and legs.

Questions 8 to 12 are related to the development of the child. The questions should be asked in the same order as listed below and responses should be elicited.

8. *Did the child sit at 6 months of age?*

9. *Did the child stand at 1 year of age?*
10. *Did the child walk at 2 years of age?*
11. *Did the child run at 3 years of age?*
12. *Did the child start speaking few words at 18 months?*
13. *Can the child speak normally (Applicable for children over 3 years of age)?* The child should be able to speak normally by the age of 3 years like the children of that age.
14. *Is the child of normal intelligence (applicable to children over 3 years of age)?* The child should be able to do the activities at home or at school like the children of the corresponding age.

### 4.2 Diagnostic criteria

For the disease under investigation a clear-cut definition must be developed in unambiguous terms to avoid errors in disease classification. In neurological practice many diagnostic and confirmatory tests are adopted for arriving at a definitive diagnosis. However, for large scale population based surveys it is not feasible to adopt a similar strategy due to cost and manpower involved. Hence "operational definitions" have to be developed to make the clinical diagnosis which is essential for the numerator component of prevalence rates and descriptions of the disease. While formulating the minimal diagnostic criteria, recourse may be taken to internationally well accepted disease definition, if considered necessary. The minimal diagnostic criteria for commonly encountered neurological disorders like epilepsy, migraine, cerebrovascular disorders, dementia, parkinson's disease, other involuntary movements and peripheral nerve disorders etc. used in BURN study are furnished in appendix viii.

### 4.3 Disease classification

Rapid retrieval and comparison of data can be facilitated by coding with the use of International Classification of diseases (ICD-10, WHO 1992). A simple diagnostic coding for common neurological disease developed for BURN study is appended (appendix ix).

## Section 5

# Recruitment and Training of Manpower

### 5.1 Composition of survey team

For neuroepidemiological studies a team of neurologist (leader of the team), epidemiologist, biostatistician and social scientist would be the ideal composition. In situations where expertise in one or more of these areas is not available, guidance and assistance of experts in the field may be sought for formulation, implementation of the study and in data analysis. In the two stage survey method usually recommended for developing countries additional staff like a medical officer can be included in the team to assist the neurologist. Some important considerations in recruiting field investigators are familiarity of area of survey, local languages and cultural practices. Previous experience in conducting health surveys would be an added advantage. The number of field investigators required depends on the size of the population, survey area, the period of study and the screening instruments used and a fair estimate can be derived from the pilot study. In BURN study, it was seen that an adequately trained field investigator could comfortably screen about 10 to 15 households (75–100 people) per day using the three performas (A,B & C).

### 5.2 Training of field staff

This is the 'critical' component of any survey programme since all final results and conclusions drawn are based on the quality of data collection. Therefore, without emphasizing the obvious, the training of the data 'collector' has to be done diligently and carefully. The training programme should focus on the following:

#### *a) Importance of survey*

Theoretical concepts underlying epidemiological surveys in general with special emphasis on neuroepidemiology, have to be imparted. The need for conducting such surveys for detection of diseases, importance of determining the magnitude and the pattern of diseases and the implications thereof in planning health services, has to be emphasized. It should be stressed that location of hospitals, selection and referral bias, awareness,

availability and acceptability of services are some of the factors which limit the utility of hospital data as a true reflection of the health status of the community.

***b) Orientation towards neurological disorders***

To explain in simple terms the role and importance of the nervous system in health and diseased states. Salient clinical features of common neurological diseases such as epilepsy, stroke, vascular headache, mental retardation, parkinsonism etc. may be highlighted. It would be vital to explain about these diseases in the commonly used terms in the local language.

***c) Method of interview***

The field investigator has to interview the identified respondent and obtain information regarding the family profile and administer the screening questionnaire, so as to detect subjects with symptoms pertaining to neurological disorders. The interview has to be conducted in the dwelling of the respondent during door-to-door survey. The field staff at the outset, should clearly state the purpose of the survey and establish rapport with the respondent and household members for conducting the interview in a cordial and non-threatening manner. The questions should be asked in the local language and dialect in a simple way so as to be easily understood by the respondent. If the response is not satisfactory, the field investigator should be informed to repeat the questions, give adequate time for recall and response and as well provide the necessary explanation indicated in the questionnaire (Section 4).

***d) Practical training***

After the field investigator is given the necessary preliminary training in understanding and administering the questionnaires (see Section 4), practical training has to be given which essentially consists of 3 steps: (i) Mock interviews (ii) Guided interviews and (iii) Field training.

*i) Mock interviews:* Interviews should be conducted by the field investigator on a group of healthy volunteers (colleagues, relatives of patients in hospital setting) to familiarize themselves with techniques and methods of interview. This will enable the project investigators to assess their ability to administer the questionnaire, elicit responses and enter data in the proforma.

Any clarifications and doubts can be appropriately explained and solutions to problems encountered in the mock interview can be offered. If the mock interviews are found to be unsatisfactory, retraining has to be provided.

*ii) Guided Interview:* Interviewing and administering the questions to the patients in the outpatient services has to be done under the supervision of the neurologist. The inter-rater and intra-rater reliability has to be established, if there are more than one investigator to ensure uniformity in data collection. Unsatisfactory performance of the field investigator or significant variation between the investigators, calls for identification of the deficiencies and implementation of corrective measures.

*iii) Field training:* The next logical step is to expose the investigators to field conditions, and adapt the interview techniques acquired through mock and guided interviews to the people in the community. The field training can be given in any suitable area, not necessarily in the chosen survey area. The interviews of respondents should be conducted under supervision of the project investigators. Field training for a week with an average coverage of 5–6 houses per day was found to be satisfactory (BURN study).

### 5.3 Period of training of field investigators

For training the field investigators to acquire comprehensive skills in theoretical and practical aspects, a minimum period of 4 to 6 weeks would be necessary.

### 5.4 Training of medical officer

If a medical officer were to be employed to assist the neurologist, similar training programme as outlined for the field investigators has to be imparted. Additional training has to be given in clinical neurological examination, recognition of salient features of common neurological disorders, diagnostic criterias and disease coding. The competence in these skills should be assessed at the end of training. The medical officer should also be trained to supervise and monitor the work of field investigators.

## Section 6

# Pilot Study

As a preliminary step to the survey of population, a pilot study usually a 2–5% of the total sample to be surveyed, needs to be conducted with the chief objectives of (a) validation of the screening questionnaire (b) adequacy of the training and (c) to plan the various components of the major survey in a systematic method. Further more, problems likely to arise in the main survey may be recognized at the pilot phase and necessary rectification done. The pilot study should be conducted in an area which is not included for the main survey. This is to avoid prior sensitization of the population to be surveyed and subsequent bias in data collection.

The field investigators should conduct house to house survey in pilot study area and identify subjects with positive symptoms through the screening questionnaire. The screened-positive subjects should be examined by the neurologist for presence of neurological disorders, thus identifying the "true positives" (confirmed to have disease) and "false positives" (confimed not to have disease). Arrangements for treatment, investigations, admission of subjects found to be suffering from neurological disorders has to be made. For non-neurological disorders, necessary steps have to be taken for providing medical care by referral to the appropriate health care agency.

A randomly chosen subsample of 10% of the pilot study sample, should be resurveyed by the neurologist to identify "false negatives" (screened negative individuals but found to have disease on clinical examination). With these steps the various indices like sensitivity and specificity can be calculated for evaluating the screening questionnaire.

In the Pilot study in urban area in Bangalore (BURN 1989-90) the following indices were determined as shown in the 2×2 contingency table below:

Indices of screening questionnaire for individuals 7 years and above

| Detection by screening instrument | Diagnosis by Neurologist | | |
|---|---|---|---|
| | Positive | Negative | Total |
| Positive | 78 | 37 | 115 |
| Negative | 4 | 2391 | 2395 |
| Total | 82 | 2428 | 2510 |

Sensitivity = 95%: Specificity = 98%

Indices of screening questionnaire for children under 7 years

| Detection by screening instrument | Diagnosis by Neurologist | | |
|---|---|---|---|
| | Positive | Negative | Total |
| Positive | 22 | 1 | 23 |
| Negative | — | 507 | 507 |
| Total | 22 | 508 | 530 |

Sensitivity = 100%: Specificity = 99%

These indices are influenced by multiple factors, some of which are dependent on the survey techniques such as development of screening questionnaire, the thoroughness of administering the questionnaire, and the disease under investigation, while, other determinants are socio-cultural-economic-educational and other characteristics of the population as well as the perception of the disease in the community. Surprisingly, other factors like availability of health services may also influence the level of sensitivity and specificity, which is illustrated by the observation of increase in prevalence rate of epilepsy when the survey was done by medical student as against that conducted by field investigators (Osuntokun 1982). In the area surveyed there were no medical facilities and therefore it was felt that the people over reported the disease for obtaining medical help.

The data should be analyzed to obtain the demographic characteristics of the population, socio-economic profile and the prevalence rates of identified neurological disorders. It would be important even at this stage to examine the association of the sociodemographic variables with the frequency and distribution of the neurological disorders, as clues may be evident for which confirmation may be sought for in the main survey.

Based on the experience derived from the pilot study, it would be possible to estimate the manpower, financial resources, materials, transportation requirements, the probable period of survey and to assess the critical managerial issues in organizing a survey of larger population.

## Section 7

# Main Study

### 7.1 Co-operation of the community

For a successful survey, it is crucial to obtain the co-operation of the community. Therefore, every attempt should be made towards this goal by appraising the community members, local political leaders, administrative officials, health personnel, religious savants and other influential people in the community about the objectives of the survey and the likely benefits accruing to the community and seek their support and cooperation. This interaction should occur not only before commencing the survey but throughout the programme and continued thereafter as well. In surveys of large magnitude, public media may also be used to sensitize the community.

### 7.2 Census information (population)

The demographic data from the latest census can be effectively used as a data base to estimate the approximate population to be surveyed. If the interval between the census and the survey is more than a few years, a revised estimate of the population has to be arrived at by standard statistical methods (arithmetic progression, geometric progression, standard growth rate or natural increase method). This information would facilitate sampling methods, allocation of work and resource management.

### 7.3 Prevalence day

In descriptive epidemiological studies, prevalence and incidence rates of the disease under consideration are determined to identify the magnitude of the problem in the community. Life time prevalence or period prevalence or point prevalence can be determined by an appropriately designed study. If not stated otherwise, prevalence rate refers to the number of persons suffering from a disease at a given point of time (point prevalence) in the community. Before commencing the survey, a decision has to be taken about the type of prevalence rate required. For determining point prevalence, the prevalence day has to be identified (e.g., first day of the year or an event or festival of importance to the local people).



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### 7.4 Data collection

The first step in data collection is enumeration which is the process of serial counting of all the individuals in the defined geographical area at a specified period of time in all their important characteristics. This forms the denominator for determining different rates. There are two approaches of enumeration: (1) Serial counting of all individuals in the survey area is undertaken as an initial step followed by administration of screening questionnaire. The advantage is that the census so derived may possibly be more accurate than the projected census estimates. The obvious disadvantage of this method is the need for excess time and other resources. (2) Simultaneous enumeration and screening can be initiated with the available census. This procedure is less time consuming and is usually preferred for the sake of convenience.

The sampling method having already been chosen, survey can be initiated to cover the entire identified population. Some important components of the data to be obtained are identification details, demographic features, family composition and socioeconomic variables like age, sex, religion, income, education, occupation, family size and family type (Appendix proforma – A). Screening questionnaire to detect adults and children with symptoms pertaining to neurological disorder is administered through a personnel interview of head of the household or surrogate respondent. The information so collected has to be entered on the data sheets (Appendix – proforma B & C).

### 7.5 Clinical evaluation

The field investigators should give an appointment for clinical evaluation of the screened positive subjects, as per prefixed schedule. Since a large number of people would require clinical evaluation, a definitive strategy has to be evolved before commencing the survey, with respect to (a) who should examine (b) where should the examination be conducted and (c) essential components of the evaluation.

(a) The individuals detected to have symptoms (screened positives) during the survey, should be examined for confirmation of the presence of neurological disorders (true positives) and exclude those with non-neurological disorders (false positives). The clinical assessment is best done by a trained neurologist, although other medical experts (general physician, neurosurgeon, paediatrician, etc) can also do the confirmatory examination; however, for the purpose of comparison among similar studies across the country and among countries, the former approach is recommended.

(b) The choice of the place of examination is a matter of convenience to the people and the research team. The different methods that can

be adopted are domicillary, satellite camps and institutional approach. The domicillary approach is the most convenient one for the individual as the services of the medical professional becomes available at the door step and furthermore this method also achieves the goal of including all screened positive subjects for clinical evaluation. The obvious limitations are that the medical professionals have to spend considerable time in travel. Another constraint would be the limited availability of time for "time bound" projects. In the satellite clinic approach the place, day and time are prefixed to enable the screened positive individuals to report at one place for clinical evaluation. It is mandatory that the identified place should be within easy reach of the community, such as local health centre, school, community hall or any other public place. This approach overcomes the limitations of the domiciliary method, thus effectively utilising the medical expertise. The satellite approach was used in our earlier in Gouribidanur study (Reddy *et al.* 1988 and Gourie-Devi *et al.* 1988). Under the institutional approach, the individuals are required to report to the institution where the research investigators are employed. While this may be feasible approach in the urban area, it would not be suitable for rural based study. Even in the urban area it was observed in the BURN study that only 25% of urban people reported to the institution and 75% had to be provided domiciliary service, despite repeated requests and assurance that clinical evaluation would be done promptly. A combination of two or more approaches may be required for satisfactory completion of clinical evaluation of all the screened positive individuals.

(c) The medical officer is given the responsibility of verification of data entry in proformas (A,B/C) of the field investigator after ascertaining the details from the patient and family members through an interview. Any addition or deletion should be made at this juncture.

Routine neurological examination should be performed to detect the presence or absence of the neurological disorders under investigation. The observations have to be meticulously recorded. Suitable proforma could be developed depending on the design of study. The proformas used in the BURN study are appended for information (Appendix iv & v). If the researcher is interested to investigate a specific disease entity, more details, addressing the various questions need to be included.

The clinical diagnosis has to be based on the diagnostic criteria and a specific code has to be entered (Appendix ix).

### 7.6 Resurvey

In the first-stage of survey, the field investigators identify subjects with symptoms (screened positives) and all the others would be considered

to be free from the disease under investigation (screened negatives). Ideally, all the "negatives" should be evaluated by the medical professional to ascertain that indeed they do not have the disease. In a large sample such a step is not feasible since logistics do not permit. An alternative approach, statistically valid and well accepted method is to obtain a representative subsample for resurvey by the medical officer. A sample of 5–10% of the screened – negatives chosen on a random basis is adequate for resurvey. This will differentiate the "true negatives" (confirmed not to have the disease) from "false negatives" (confirmed to have the disease) and reflect the quality of survey by the field investigators. The corrective measures, if found necessary, could be undertaken at this stage.

Resurvey should be a continuous process and concurrent with the progress of survey e.g., resurvey of surveyed village, taluk or a defined area in city should be undertaken soon after completion of the survey of the area since mid-course remedial measures are possible. It is not advisable to postpone the resurvey to the end of the survey.

## 7.7 Some issues for consideration in field surveys

### *(a) Inaccessibility of survey site*

In the remote villages of the developing countries due to nonexistence of motorable roads and flooding during monsoon, it may not be possible to reach the survey site inspite of taking recourse to local means of transportation such as bullock carts, cycles, etc. Therefore it is important to plan the survey during the period of the year most suitable for that region.

### *(b) Number and gender of field workers for survey*

A survey of a household can be done by one field worker or a pair of field workers, both these approaches having merits and demerits. With one field worker doing the survey, a short questionnaire may be easily dealt with, but if there are long questionnaires, then it may be necessary for one field worker to conduct the interview and the other to simultaneously enter the responses thus speeding up the progress of interview. When surveys are addressed to answer specific questions related to sexual practices, gynaecological and obstetric problems, women field workers would be preferable.

### *(c) Unoccupied, abandoned and locked houses*

Unoccupied or abandoned houses encountered in the survey area, after ascertaining the occupancy status should be excluded from the survey. Locked houses with the residents away from the house can be a problem

in both urban and rural areas. To surmount the problem and include the occupants in the survey, it would be necessary to revisit the houses at the time when head of the household would be available for interview, e.g., during weekends, early or late hours of the day, or on holidays. All efforts should be made to keep "loss of sample" to a bare minimum so as to attain maximum coverage possible. Inspite of repeat visits, atleast 3 to 4 times, if the houses are found to be locked, such houses can be excluded. Such situations may also arise under different circumstances like unwillingness or lack of interest of the residents to participate in the survey and temporary migration.

***(d) Interviewee: Head of the household or individual members?***

Ideally every adult member of the household should be interviewed, but due to resource constraints it may not be feasible and therefore in many surveys the head of the household is interviewed about the health status of all the family members (Gourie-Devi *et al.* 1991: Anderson and Kalton 1990). In the Indian context and perhaps in many other Asian countries, the head of the household occupies a venerable position in closely knit family and is aware of health problems of all the members of the family. Since most of the neurological disorders are either acute or chronic and progressive with considerable disability or paroxysmal with "dramatic element", they are easily perceived by the head of the household.

***(e) Emotional reactions of respondents***

While most of the respondents react to questions appropriately, some may express fear, anger, or may appear puzzled. Fear is usually a result of ignorance about the disease under question and can be usually overcome by proper explanation and infusing confidence. This situation in the context of neuroepidemiology often arises with reference to epilepsy and mental retardation. Questions aimed at eliciting information about sexual behaviour and illnesses carrying stigma like mental disorders, epilepsy, leprosy may lead to the respondent angrily reacting to it. If the field investigators cannot overcome this problem by suitable replies, it may be necessary for the medical officer to personally interview such people. Assurance of the anonymity of the data collected also helps in allaying the fears and anxiety.

***(f) Non-cooperation of the respondent***

A major hurdle faced in survey would be non-cooperation of respondent due to misinformation about the disease under survey because of repeated surveys dealing with a variety of health parameters and diseases. A special effort has to be made by the research investigators to disseminate

the information regarding the implication and need of neuroepidemiological survey including the impact on the health care delivery. The inbuilt health education measures, making the interviews pleasant and nonthreatening and provision of necessary services for diagnosis and management will go a long way in obtaining the confidence and cooperation of the community.

## Section 8

# Monitoring and Supervision

Monitoring and supervision of the staff engaged in the survey is central to the success of the survey. Monitoring essentially is a continuous process to oversee that the activities are progressing according to the preplanned schedules, managerial and logistics aspects are taken into account, targets are completed on time and quality control procedures are established. Since in the suggested neuroepidemiological survey a two tier concept has been envisaged, with the field investigators forming the first tier and the medical officer forming the second tier, the monitoring should occur at different levels. The medical officer should monitor the work of field investigators on a daily basis. If the medical officer is other than the neurologist, the latter should monitor the work of medical officer as well as field investigators independently.

Methods of monitoring vary in different surveys and depend on the magnitude of survey, size of the area, distribution of the sample and resources. The various methods commonly employed are resurvey, random checks, surprise visits, key informant enquiries, cross enquiries and random telephonic enquiries. A subset of surveyed houses, proformas, people interviewed and screened positives chosen randomly are re-evaluated by the project investigators.

Monitoring should be closely interwoven with different activities of the survey at the field level during data collection, clinical assessment, resurvey and data entry. The field investigator's work has to be closely monitored. To facilitate the process a monitoring form was developed for the BURN study (Appendix vii). The number of houses surveyed and those which could not be surveyed with reasons for non-completion, the total number of people (adults and children) enumerated, number of people detected to be positive on screening questionnaire and those who have undergone clinical assessment are regularly and promptly entered in this form. The information so gathered provides a ready reference to the progress of the survey and the status at any given point of time. Although the procedure outlined appears cumbersome, it is important to keep a close watch of the day to day work of every member of the survey team. Periodic meeting with the field team should be held to identify practical problems at the field level and necessary solutions offered.

## Section 9

# Providing Health Care

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Human ethics demand that services need to be provided for any individual with disease. Therefore, a harmonious blending of survey with service is absolutely mandatory. Depending on the need of the patient the necessary investigations and treatment have to be provided. If need be, appropriate referrals to hospital or speciality service should be made for providing further care. For the economically needy, provision may be made for free drug supply. This humane approach often establishes a continuing rapport between the community and the research team. There should be inbuilt mechanisms to increase awareness and disseminate information about the disease and emphasize the need for the continuity of care and, rehabilitation to minimize disabilities due to neurological disorders. Active and enthusiastic participation of the community at large, with vigorous support from governmental and non-governmental agencies, religious institutions and philanthropists will facilitate the development of such community based programmes.

## Section 10

# Data Analysis and Utilisation

Data entered in the proformas has to be verified for clarity, completeness and coding. Since manual handling of such voluminous data is not feasible, computer usage is advocated. Concurrent entry of data with the help of standard packages (dBase, Epi-Info and others) facilitates prompt correction and avoids backlog and time delays.

Type and depth of data analysis depend on the stated objectives of the project and the interest of the researcher. The analysis usually starts with the frequency distribution of sociodemographic and illness related variables. Furthermore, this could be stratified into various groups based on the range and distribution pattern. Since the chief objective of descriptive epidemiological surveys is to determine magnitude and distribution of neurological disorders as the first step, crude prevalence rates can be determined. Further analysis allows determination of specific rates such as age specific or age adjusted rates, which provide a more realistic data than the crude rates and also enable comparison between different studies within the region or across countries. The next logical step is to examine the association of the disease with a number of factors and formulate a hypothesis towards understanding the causal mechanism underlying the disease process.

In many developing countries speciality services like neurology are not available to the majority due to lack of expert manpower and financial resources. To realistically plan the needs of the community, the data emerging from neuroepidemiological studies is used as the basis for developing manpower, diagnostic and managerial services, provision of adequate and continuous supply of drugs, organizing rehabilitation services and finally develop an integrated and comprehensive approach for management of patients with neurological disorders at the primary, secondary and tertiary levels of health care delivery system. The fulfillment of judicious use of available financial resource for health care is possible by a sensible use of the data from such surveys.

A clustering of patients in a geographical area, may indicate an impending outbreak while an unexpected cluster of a rare disorder may lead to new avenues of research. Status of health care services can also

be assed by the detection of clusters, eg. in Gouribidanur survey the prevalence of poliomyelitis sequelae was high (99/1,00,000) reflecting poor immunization coverage (Gourie-Devi *et al.* 1987). In the same study prevalence rate of 23 per 100,000 of postencephalitic sequelae was tell-tale evidence of the Japanese encephalitis epidemic 3 years prior to the survey.

Although the purpose of screening using a questionnaire in surveys is primarily to detect the individuals with disease and determine prevalence rates, a more important outcome from the health care point of view is that it is possible to screen a large population and provide the necessary care. Very often the affected individuals might not have been aware of the disease or the availability of diagnostic and treatment facilities and therefore would not seek medical attention. A corollary is that a disease may be detected at the initial stages and with appropriate intervention measures may lead to either complete recovery or minimize residual deficits, disability, deformity and resultant handicap.

Descriptive epidemiology provides the foundation for all further, long term, focused analytical studies (case control, cohort) for risk factor identification and quantification along with possible clues to the aetiopathogenesis. The next appropriate strategy is to develop intervention methods and conduct well designed experimental epidemiological (intervention trials) researches towards identifying the optimum therapeutic modalities and strategies towards control of diseases.

## Section 11

# Bibliography

## References


1. Abraham, J., Rao, P.S., Inbaraj, S.G., Shetty, G., Jose, C.J. An epidemiological study of Hemiplegia due to stroke in South India. Stroke, 1, 477-481, 1970.
2. Anderson, D.W., and Kalton, G. Case-finding Strategies for studying rare chronic diseases. Statistica Applicata, 23, 309-321, 1990.
3. Bharucha, N.E., Bharucha, E.P., Dastur, H.D., Schoenberg, B.S. Pilot survey of the prevalence of neurologic disorders in the Parsi community of Bombay. American Journal of Preventive Medicine, 3, 293-299, 1987.
4. Dalal, P.M., Strokes (CVD) in India. Japanese Circulation Journal 46, 621-624, 1982.
5. Gourie-Devi, M., Rao, V.N., Prakshi, R. Neuroepidemiological study in Semiurban and rural areas in South India: Pattern of Neurological disorders including motor neurone disease. In: Motor Neurone Disease – Global Clinical Patterns and International Research. Ed: M. Gourie-Devi, Oxford & IBH Publishing Company Pvt Ltd. Bombay, 11-21, 1987.
6. Gourie-Devi, M. Can India afford Neuroepidemiology? (Editorial). Neurology India, 35, 125-127, 1987.
7. Gourie-Devi, M., Rao, V.N., Prakashi, R. A protocol to detect neurological disorders in the community. Indian Journal of Medical Research, 88, 443-449, 1988.
8. Gourie-Devi, M., Anderson, D.W., Rao, V.N. Neuroepidemiologic survey in a developing country: Some questions and answers. In: Neuroepidemiology: A tribute to Bruce Schoenberg. Anderson, D.W. (Ed.) CRC Press, Boston, 12-23, 1991.
9. Gourie-Devi, M., Gururaj, G. Vasisth, S., Subbakrishna, D.K. Risk Factors in Monomelic Amyotrophy – A Case Control Study. NIMHANS Journal, 11, 79-87, 1993.
10. Gururaj, G. and Satishchandra, P. Correlates of Hot-Water epilepsy in rural South India: A descriptive study. Neuroepidemiology, 11, 173-179, 1992a
11. Gururaj, G., Satishchandra, P., Banerjee, D., Alphonsa, M., Subbakrishna, D.K. Importance of mortality statistics in epidemiology of neurological disorders. NIMHANS Journal, 10, 17-21, 1992b.
12. Hennekens, C.H. and Buring, J.E. Epidemiology in Medicine, (Ed) Mayrent, S.L., Little Brown and Company, Boston, 327-347, 1987.
13. Kapoor, S.K., Chandra, V., Banerjee, A.K., Nath, L.M., Schoenberg, B.S. Pilot study of the prevalence of major neurologic disorders in a rural population of India. Neuroepidemiology, 9, 287-295, 1990.
14. Kurtzke, J.F. Neuroepidemiology. Annals of Neurology, 16, 265-277, 1984.
15. Kurtzke, J.F. Neuroepidemiology Part II: Assessment of therapeutic trials. Annals of Neurology, 19, 311-319, 1986.
16. Li, S., Schoenberg, B.S., Wang, C., Cheng, X., Zhou, S. Bolis, C.L. Epidemiology of epilepsy in urban areas of the People's Republic of China. Epilepsia, 26, 391-394, 1985.
17. Mathai, V.K. Investigation into methods for rehabilitation of persons disabled by convulsive disorders. SRS Project No. 19-P-58113 Fol. HEW Washington DC and ICMR 1969.

18. Meneghini, F., Rocca, W.A., Grigoletto, F., Morgante, L., Reggio, A., Savettier, S., Perri, R.D., Anderson, D.W. Door-to-Door prevalence survey of neurological disease in a Sicilian population. Neuroepidemiology, 10, 70-85, 1991.
19. Osuntokun, B.O., Schoenberg, B.S., Nottidge, V.A., Adeuja, A., Kale, O., Adeyefa, A., Bademosi, O., Olumide, A., Oyediran, A.B.O., Pearson, C.A., Bolis, C.L. Research protocol for measuring the prevalence of neurologic disorders in developing countries. Neuroepidemiology, 1, 143-153, 1982.
20. Razdan, S., Kaul, R.L., Motta, A., Kaul, S., Bhatt, R.K., Prevalence and pattern of major neurological disorders in rural Kashmir. Neuroepidemiology 13, 113-119, 1994.
21. Reddy, G.N.N., Channabasavanna, S.M., Gourie-Devi, M., Das, B.S., Prabhu, G.G., Shariff, I.A., Kaliaperumal, V.G., Reddamma, K. Extension of mental health services by Satellite clinics as a model. NIMHANS Journal 4, 71-75, 1986.
22. Romdhane, N.A., Hamida, M.B., Mrabet, A., Larnaout, A. Samoud, S., Hamada, A.B., Handa, M.B., Queslati, S., Prevalence study of neurologic disorders in Kelibia (Tunisia) Neuroepidemiology, 12, 285-299, 1993.
23. Sander, J.W.A.S. and Shorvon, S.D., Incidence and prevalence studies in epilepsy and their methodological problems: a review. Journal of Neurology, Neurosurgery and Psychiatry, 50, 829-839, 1987.
24. Satishchandra, P., Chandra, V., Schoenberg, B.S. Case-control study of associated conditions at the time of death in patients with epilepsy. Neuroepidemiology, 7, 109-114, 1988.
25. Schoenberg, B.S. Clinical Neuroepidemiology in developing countries: Neurology with few neurologists. Neuroepidemiology, 1, 137-142, 1982.
26. Weddell, J.M. Applications of a stroke register in planning. In: Clinical Neuroepidemiology (Ed) Rose, C. Pitman Medical Limited, Kent, 112-127, 1980.
27. WHO Research Protocol for measuring the prevalence of Neurological disorders in developing countries. Neuroscience Programme, Geneva, World Health organisation, 1981.
28. World Health Organisation – International Statistical Classification of Diseases and Related Health Problems. (ICD-10) Tenth Revision, Geneva, 1992.

## Selected reading

1. Ahlbom, A. and Norell, S. Introduction to Modern Epidemiology. Epidemiology Resources Inc. MA, 1990.
2. Barker, D.J.P. Practical Epidemiology, Second Edition, ELBS & Churchill Livingstone, Edinburgh, 1978.
3. Friedman, L.M., Furberg, C.D. & Demets, D.L. Fundamentals of Clinical Trials. Second Edition. PSG Publishing Company, Inc. Massachusetts, 1985.
4. Kendall, M.G. and Buckland, W.R. A Dictionary of Statistical Terms. Third Edition, Hafner Publishing Company, New York. 1972.
5. Koprowski, C.D., Longstretch, W.T. Jr., Cebul, R.D. Clinical neuroepidemiology, III. Decisions. Archives of Neurology, 46, 223-229, 1989.
6. Last, J.M., A Dictionary of Epidemiology. Second Edition, Oxford University Press, New York, 1988.
7. Longstretch, W.T. Jr., Koepsell, T.D., van Belle, G. Clinical neuroepidemiology. I. Diagnosis. Archives of Neurology 44, 1091-1099, 1987.
8. Longstretch, W.T., Jr., Koepsell, T.D., van Belle, G. Clinical neuroepidemiology II, Outcomes. Archives of Neurology, 1196-1202, 1987.
9. Lilienfeld, A.M. and Lilienfeld, D.E. Foundations of Epidemiology, Second Edition, Oxford University Press, New York, 1980.
10. Lwanga, S.K. and Lemeshow, S. Sample size determination in health studies: A practical manual. World Health Organisation, 1991.
11. Rothman, K.J., Modern Epidemiology. Little, Brown and Company, Boston, 1986.

12. Schlesselman, J.J., Case Control Studies: Design, Conduct, Analysis, New York, Oxford University Press, 1982.

13. Sackett, D.L., Haynes, R.B. and Tugwell, P. Clinical Epidemiology – A Basic Science for Clinical Medicine. Little, Brown and Company, Boston, 1985.

14. Rao, P.S.S., Jesudian, G. and Richard, J., Introduction to Biostatistics. A Manual for Students in Health Sciences, Second Edition, Vellore, 1987.

15. Neuroepidemiology: Theory & Method, (Ed) Molgaard, C.A. Academic Press, Inc. New York, 1993.

16. Clinical Neuroepidemiology: Progress in Neurological Research Series, Rose, F.C. (Ed) Pitman Medical Ltd. Kent, 1980.

17. Advances in Neurology, vol. 19 Schoenberg, B.S. (Ed) Raven Press, New York, 1978.

18. Neuroepidemiology: A Tribute to Bruce Schoenberg, Anderson, D.W. (Ed) CRC Press, Boston, 1991.

## Section 12

# Glossary of Terms

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1. **Age-specific rate :** A rate for a specified age group. The numerator and denominator refer to the same age group.

$$\text{Age-specific death rate (age 25-34)} = \frac{\text{No. of deaths among residents age 25-34 in an area in a year}}{\text{Average (or mid year) population age 25-34 in the area in that year}} \times 100{,}000$$

2. **Area sampling :** A method of sampling that can be used when the numbers in the population are unknown. The total area to be sampled is divided into subareas, e.g by means of a grid that produces squares on a map; these subareas are then numbered and sampled, using a table of random numbers. Depending upon circumstances, the population in the sampled areas may first be enumerated, then a second stage of sampling may be conducted.

3. **Bias :** Deviation of results or inferences from the truth, or processes leading to such deviation. Any trend in the collection, analysis, interpretation, publication, or review of data that can lead to conclusions that are systematically different from the truth are among the ways in which deviation from the truth can occur.

4. **Case control study :** (Syn : case comparison study, case compeer study, case history study, case referent study, retrospective study) A study that starts with the identification of persons with the disease (or other outcome variable) of interest, and a suitable control (comparison, reference) group of persons without the disease. The relationship of an attribute to the disease is examined by comparing the diseased and non diseased with regard to how frequently the attribute is present or, if quantitative, the levels of the attribute, in each of the groups. Such a study can be called "retrospective" because it starts after the onset of disease and looks back to the postulated causal factors. Cases and controls in case control study may be accumulated "prospectively"; that is, as each new case is diagnosed it is entered in the study. Neverthless, such a study may still be called "retrospective" because it looks back from the outcome to its causes. The terms "cases" and "controls" are sometimes used to describe subjects in a RANDOMIZED CONTROLLED TRIAL but, the term "case controlled study" should not be used to describe such a study. The tems "case control study" and "retrospective study" have been used most often to describe this method. Other terms also used are listed above.

5. **Census :** An enumeration of a population, originally intended for purposes of taxation and military service. Census enumeration of a population usually records identities of all persons in every place of residence, with age, or birth date, sex, occupation, national origin, language, marital status, income, and relationship to head of house hold, in addition to information on the dwelling place. Many other items of information may be included, e.g. educational level (or literacy) and health-related data such as permanent disability. A de facto census allocates persons according to their location at the time of enumeration. A de jure census assigns persons according to their usual place of residence at the time of enumeration.

6. **Central tendency:** The tendency of quantitative data to cluster around some variate value. The position of the central value is usually determined by one of the measures of location

such as Mean, Median or Mode. The closeness with which values cluster around the central value is measured by one of the measures of dispersion such as the Mean Deviation or Standard Deviation.

7. **Classification of disease :** Arrangement of disease into groups having common characteristics. Useful in efforts to achieve standardization, and therefore comparability, in the methods of presentation of mortality and morbidity data from different sources. May include a systematic numerical notation for each disease entry.

   Example include the INTERNATIONAL CLASSIFICATION OF DISEASES, INJURIES and CAUSES OF DEATH (ICD) and THE INTERNATIONAL CLASSIFICATION OF HEALTH OF PROBLEMS IN PRIMARY CARE (ICHPPC).

8. **Clinical epidemiology:** The use of epidemiological principles, methods and findings in personal health care or community-oriented primary care, with special reference to applications in diagnostic and prognostic appraisal, decisions concerning care and the evaluation of care. The term sometimes refers to any epidemiological study conducted in a clinical setting.

9. **Clinical trial:** A research activity that involves the administration of a test regimen to humans to evaluate its efficacy and safety. The term is subject to wide variation in usage, from the first use in humans without any control treatment to a rigorously designed and executed experiment involving test and control treatments and randomization.

10. **Cluster sampling:** When the basic sampling unit in the population is to be found in groups or cluster, eg. human beings in households, the sampling is sometimes carried out by selecting a sample of clusters and observing all the members of each selected clusters. This is known as cluster sampling. If the elements are closely grouped they are said to be compact. If they are almost equivalent to a geographically compact group from the point of view of investigational convenience they are said to be quassi-compact.

11. **Cohort study:** (Syn: concurrent, follow-up, incidence, longitudinal, prospective study) The method of epidemiologic study in which subjects of a defined population can be identified who are, have been, or in the future may be exposed in different degrees, to a factor or factors hypothesized to influence the probability of occurence of a given disease or other outcome. The alternative terms for a cohort study, i.e., follow-up, longitudinal, and prospective study, describe an essential feature of the method, which is observation of the population for a sufficient number of person-years to generate reliable incidence of mortality rates in the population subsets. This generally implies study of a large population or study for a prolonged period (years), or both.

12. **Community:** A group of individuals organized into a unit, or manifesting some unifying trait or common interest; loosely, the locality or catchment area population for which a service is provided, or more broadly, the state, nation or body politic.

13. **Community diagnosis:** The process of appraising the health status of a community, including assembly of vital statistics and other health-related statistics and of information pertaining to determinants of health, such as prevalence of tobacco smoking, and examination of the relationships of these determinants to health in the specified community. The term may also denote the findings of this diagnostic process. Community diagnosis may attempt to be comprehensive, or may be restricted to specific health conditions, determinants, or subgroups.

14. **Comorbidity:** Disease(s) that coexist(s) in a study participant in addition to the index condition that is the subject of study.

15. **Contingency table:** A tabular cross-classification of data such that subcategories of one characteristic are indicated horizontally (in rows) and subcategories of another characteristic are indicated vertically (in columns). Tests of association between the characteristics in the columns and rows can be readily applied. The simplest contingency table is the fourfold, or $2\times2$ table. Contingency tables may be extended to include several dimensions of classification.

16. **Demograpy:** The study of populations, especially with reference to size and density, fertility, mortality, growth, age distribution, migration, and VITAL STATISTICS, and the interaction of all these with social and economic conditions.

17. **Descriptive study:** A study concerned with and designed only to describe the existing distribution of variables, without regard to causal or other hypotheses. Contrast analytic study. An example is a community health survey, used to determine the health status of the people in a community. Descriptive studies e.g. analyses of cancer registry data can be used to measure risks.

18. **Direct sampling:** A term used when the sample units are actual members of the population and not, for instance, some kind of record relating to such numbers, such as census form, ticket or registration card. The term relates to the directness of the observation of the units which enter into the sample, not to the process by which they are selected.

19. **Epidemiology:** The study of the distribution and determinants of health-related states or events in specified populations and the application of this study to control of health problems. There have been many definitions of epidemiology. In the past 50 years or so, the definition has broadened from concern with communicable disease epidemics to take in all phenomena related to health in populations.

20. **Epidemiology, descriptive:** Study of the occurrence of disease or other health-related characteristics in human populations. General observations concerning the relationship of disease to basic characteristics such as age, sex, race, occupation, and social class, also concerned with geographic location. The major characteristics in descriptive epeidemiology can be classified under the headings; persons, place and time.

21. **Errors in survey:** The errors in a sample survey arise both from sampling effects and from other source not connected with sampling, i.e. they would also be present for a complete survey. It has become customary to use the word 'error' to cover all these types of departures from representativeness, whereas in some statistical contexts 'error' denotes 'sampling error' and the other effects are called 'biasses'.

22. **Estimation:** Estimation is concerned with inference about the numerical value of unknown population values from incomplete data such as sample. If a single figure is calculated for each unknown parameter the process is called point estimation. If an interval is calculated within which the parameter is likely, in some sense, to lie, the process is called interval estimation.

23. **Exhaustive sampling:** A term occasionally encountered which indicates that, in order to achieve the sample size necessary for the required precision, the sampling has included all of the population under study. That is to say that a complete enumeration rather than a sample has been taken.

24. **Extensive sampling:** A term used to denote sampling where the subject matter, geographical coverage, of a sample is diffuse or widespread as opposed to intensive, where it is narrowed to a small field. Extensive sampling may refer either to a case where a wide variety of topics are covered superficially, rather than a few topics in detail or a large area is surveyed broadly, rather than a small area studied in detail. The term could also be used with reference to time, that is to say, of sampling covering a long period. It would be convenient to distinguish the cases as space-extensive, item-extensive and time-extensive respectively.

25. **False negative:** Negative test result in a subject who possesses the attribute for which the test is conducted. The labeling of a diseased person as healthy when screening in the detection of disease.

26. **False positive:** Positive test result in a subject who does not possess the attribute for which the test is conducted. The labeling of a healthy person as diseased when screening in the detection of disease.

27. **Family:** A group of two or more persons united by blood, adoptive or marital ties, or the common law equivalent; the family may include members who do not share the household but are united to other members by blood, adoptive or marital or equivalent ties. Epidemiologic studies may be concerned with family members or with those who share the same household or dwelling unit.

28. **Family, extended:** A group of persons comprising members of several generations united by blood, adoptive and marital or equivalent ties.

29. **Family, nuclear:** A group of persons comprising members of a single or at most two generations, usually husband-wife-children, united by blood or adoptive and marital or equivalent ties.

30. **Frame:** A list, map or other specification of the units which constitute the available information relating to the population designated for a particular sampling scheme. There is a frame corresponding to each stage of sampling in a multi-stage sampling scheme. The frame may or may not contain information about the size or other supplementary information of the units, but should have enough details so that a unit, if included in the sample, may be located and taken up for inquiry. The nature of the frame exerts a considerable influence over the structure of a sample survey. It is rarely perfect, and may be inaccurate, incomplete, inadequately described, out of date or subject to some degree of duplication. Reasonable reliability in the frame is a desirable condition for the reliability of a sample survey based on it.

    In multi-stage sampling it is sometimes possible to construct the frame at higher stages during the progress of the sample survey itself. For example, certain first stage units may be selected in the first instance; and then more detailed or maps may be constructed by compilation of available information or by direct observation only of the first-stage units actually selected.

31. **Frequency:** The number of occurrences of a given type event, or the number of members of a population falling into a specified class. It is a general term without distinguishing between incidence and prevalence.

    Where the frequency is expressed as proportion of the total number of occurrences or the total number of members, it is called the relative or proportional frequency. But where no ambiguity can arise these ratios may simply be called frequencies.

32. **Health care:** Those services provided to individuals or communities by agents of the health services or professions, for the purpose of promoting, maintaining, monitoring or restoring health. Health care is broader than, and not limited to medical care, which implies therapeutic action by or under the supervision of a physician. The term is sometimes extended to include self-care.

33. **Health statistics:** Aggregated data describing and enumerating attributes, events, behaviors, services, resources, outcomes or costs related to health, disease and health services. The data may be derived from survey instruments, medical records, and administrative documents. VITAL Statistics are a subset of health statistics.

34. **Health survey:** A survey designed to provide information on the health status of population. It may be descriptive, exploratory or explanatory.

35. **Hypothesis:** 1. A supposing, arrived at from observation or reflection, that leads to refutable predictions. 2. Any conjecture cast in a form that will allow it to be tested and refuted.

36. **Incidence:** The number of instances of illness commencing, or of persons falling ill, during a given period in a specified population. More generally, the number of new events, e.g., new cases of disease in a defined population, within a specified period of time. The term incidence is sometimes used to denote INCIDENCE RATE.

37. **Incidence rate:** The rate at which new events occur in a population. The numerator is the number of new events that occur in a defined period; the denominator is the population at risk of experiencing the event during this period, sometimes expressed as person-time. The incidence rate most often used in public health practice is calculated by the formula

$$\text{Incidence rate} = \frac{\text{Number of new events in specified period}}{\text{Number of persons exposed to risk during this period.}} \times 10^n$$

38. **Indirect sampling:** Sampling from documents, or some record of the characteristics of a population, rather than the recording of information obtained at first hand from units of the population, themselves. For example, it is becoming customary to obtain preliminary information on the results of , say, a national census by analysing a sample of the census forms before the full analysis is undertaken; the population is then subject to indirect sampling.

39. **Intensive sampling:** Like extensive sampling this expression may mean two different things either (a) sampling in a particular area with a dense scatter of sampling points or (b) sampling wherein information on a restricted range of topics is sought by probing on them very deeply with an intricate schedule of questions.

40. **Line sampling:** A method of sampling in a geographical area. Lines are drawn and all members of the population falling on the line, or intersected by it, are included in the sample. If the lines are straight parallels equally spaced across the area concerned, then the sampling becomes one form of systematic sampling. If, instead of all intercepts on the lines are chosen on each line the sampling is equivalent to choosing the points on a lattice and may also be regarded as two stage sampling.

41. **Lottery sampling:** A method of drawing random samples from a population by constructing a miniature of the population, eg. by inscribing the particulars of each member on to a card and drawing members at random from it, eg. by shuffling the cards and dealing a set haphazardly. It is the method usually employed at a lottery, hence its name, but suffers from the disadvantage that the preparation of the cards entails considerable labour and strict precautions must be taken in the shuffling process to guard against bias.

42. **Master sample:** A sample drawn from a population for use on a number of future occasions, so as to avoid ad hoc sampling on each occasion. Sometimes the master sample is large and subsequent inquiries are based on a subsample from it.

43. **Mixed sampling:** Where a sampling plan envisages the use of two or more basic methods of sampling it is termed mixed sampling. For example, in a multi-stage sample, if the sampling units at one stage are drawn at random and those at another by a systematic methods, the whole process is 'mixed'.

44. **Monitoring:** 1. The performance and analysis of routine measurements, aimed at detecting changes in the environment or health status of populations. Not to be confused with SURVEILLANCE. To some, monitoring also implies intervention in the light of observed measurements. 2. Ongoing measurement of performance of a health service or a health professional, or of the extent to which patients comply with or adhere to advice from health professionals. 3. In management, the continuous oversight of the implementation of an activity that seeks to ensure that input deliveries, work schedules, targeted outputs, and other required actions are proceeding according to plan.

45. **Morbidity survey:** A method for estimating the prevalence and or incidence of disease or diseases in a population. A morbidity survey is usually designed simply to ascertain the facts as to disease distribution, and not to test a hypothesis.

46. **Multi-phase sampling:** It is sometimes convenient and economical to collect certain items of information from the whole of the units of a sample and other items of usually more detailed information from subsample of the units constituting the original sample. This may be termed two phase sampling, eg. if the collection of information concerning variate, y, is relatively expensive, and there exists some other variate, x, correlated with it, which is relatively cheap to investigate, it may be profitable to carry out sampling in two phases. At the first phase, x is investigated, and the information thus obtained is used either (a) to stratify the population at the second phase, when y is investigated, or (b) as supplementary information at the second phase, a ratio or regression estimate being used. Two phase sampling is sometimes called 'double sampling'. Further phases may be added if desired. It may be noted, however, that multi-phase sampling does not necessarily imply the use of any relationships between the variates x and y. The expression is not to be confused with Multi-stage Sampling.

47. **Nonresponse:** In sample surveys failures to obtain information from a designated individuals for any reason (death, absence, refusal to reply) is often called a non response and the proportion of such individuals of the sample aimed at is called the nonresponse rate. It would be better, however to call this a 'failure' rate or a 'nonachievement' rate and to confine 'nonresponse' to those cases where the individual concerned is contacted but refuses to reply or is unable to do so for reason such as deafness or illness.

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Non-availability of information in other situations, eg. arrival of the investigator for crop cutting experiments after harvesting, may also be termed nonresponse, or better, non-achievement.

When several items of information are to be collected for the same sample unit, it may so happen that information is not available for some of the items but available for others. The term nonresponse is usually not applied in such a situation; but incomplete response or incomplete achievement may be used.

48. **Pilot survey:** A survey, usually on a small scale, carried out prior to the main survey, primarily to gain information to improve the efficiency of the main survey. For example, it may be used to test a questionnaire, to ascertain the time taken by field procedure or to determine the most effective size of the sample unit.

The term 'exploratory survey' is also used, but in the rather more special circumstances when little is known about the material or domain under inquiry.

49. **Point survey:** A method of sampling a geographical area by selecting points on it, espcially by choosing points at random on a map or aerial photograph.

50. **Population:** 1. All the inhabitants of a given country or area considered together. 2. (In sampling) The whole collection of units from which a sample may be drawn; not necessarily a population of persons; the units may be institutions, records or events. The sample is intended to give results that are representative of the whole population.

51. **Prevalence:** The number of instances of a given disease or other condition in a given population at a designated time; sometimes used to mean PREVALENCE RATE. When used without qualification the term usually refers to the situtation at a specified point in time (point prevalence)

Prevalence, Annual: The total number of persons with the disease or attribute at any time during a year. It includes cases of the disease arising before but extending into or through the year as well as those having their inception during the year.

Prevalence, Lifetime: The total number of persons known to have had the disease or attribute for a at least part of their life.

Prevalence, Period: The total number of persons known to have had the disease or attribute at any time during a specified period.

Prevalence, Point: The number of persons with a disease or an attibute at a specified time.

52. **Prevalence rate:** The total number of all individuals who have an attribute or disease at a particular time (or during a particular period) divded by the population at risk of having the attribute or disease at this point in time or midway through the period. A problem may arise with calculating period prevalence rates because of the difficulty of defining the most appropriate denominator.

53. **Probability sampling:** Any method of selectiuon of a sample based on the theory of probability; at any stage of the operation of selection the probability of any set of units being selected must be known. It is the only general method known which can provide a measure of precision of the estimate. Sometimes the random sampling is used in the sense of probability sampling.

54. **Purposive sampling:** A sample in which the individual units are selected by some purposive method. It is therefore subject to biases of personal selection and for this reason is now rarely advocated in its crude form.

55. **Quality control:** The supervision and control of all operations involved in a process, usually involving sampling and inspection, in order to detect and correct systematic or excessively random variations in quality.

56. **Quota sampling:** A sample, usually of human beings, in which each investigator is instructed to collect information from an assigned number of individuals (the quota) but the individuals are left to his personal choice. In practice this choice is severely limited by 'controls' eg. he is instructed to secure certain numbers in assigned age groups, equal number of the two sexes, certain numbers in a particular social classes and so forth. Subject to these controls, which

which are designed to make the sample as representative as possible, he is not restricted to the contacting of assigned individuals as in most forms of probability sampling.

57. **Random:** This word may be taken as representing an undefined idea, or if defined, must be expressed in terms of the concept of probability. A process of selection applied to a set of objects is said to be random if it gives to each one an equal chance of being chosen. Generally, the use of the word 'random' implies that the process under consideration is in some sense probabilistic.

58. **Random distribution:** This expression is sometimes wrongly used for a probability distribution. It is also sometimes employed to denote a distribution of probability which is uniform in the range concerned, i.e. a rectangular distribution. It seems better to avoid the term altogether, or, in such expression as 'point randomly distributed over an area' to specify clearly the law of distribution invloved.

59. **Random selection:** A method of selecting sample units such that each possible sample has a fixed and determinate probability of selection. Ordinary haphazard or seemingly purposeless choice is generally insufficient to guarantee randomness when carried out by human beings and devices such as tables of random sampling numbers, or analogus machines, are used to remove subjective biases inherent personal choice.

60. **Randomization:** Randomization or random assignment should not be confused with haphzard assignment. Random assignment follows a predetermined plan that is usually devised with the aid of a table of random numbers. The pattern of assignment may appear to be haphazard, but this arises from the haphazard naure with which digits occur in a table of random numbers, and not from the haphazard whim of the investigator in allocating patients.

61. **Rate:** A rate is a measure of the frequency of a phenomenon. In epidemiology, demography, and vital statistics, a rate is an expression of the frequency with which an event occurs in a defined population; the use of rates rather than raw members is essential for comparision of experience between populations at different times, different places, or among different classes of persons.

The components of a rate are the numerator, the denominator, the specified time in which events occurs, and usally a multiplier, a power of 10, which converts the rate from an awkward fraction or decimal to whole number:

$$\text{Rate} = \frac{\text{Number of events in specified period}}{\text{Average population during the period}} \times 10^n$$

All rates are ratios, calculated by dividing a numerator, e.g. the number of deaths, or newly occuring cases of a disease in a given period, by a denominator e.g., the average population during that period. Some rates are proportions, i.e. the numerator is contained within the denominator.

62. **Ratio:** The value obtained by dividing one quantity by another: a general term of which rate, proportion, percentage, etc. are subsets. The important difference between a proportion and a ratio is that the numerator of proportion is included in the population defined by the denominator, whereas this is not necesarily so for a ratio. A ratio is an expression of the relationship between a numerator and a denominator where the two usually are separate and distinct quantities, neither being included in the other.

63. **Refusal rate:** In the sampling of human populations, the proportion of individuals who, though successfully contacted, refuse to give the information sought. The proportion is usually and preferably calculated by diving the number of refusals by the total number of the sample which it was originally desired to achieve. Where, however, there are other causes of non-achievement, eg. persons have died or left the area, the refusal rate is sometimes calculated as the number of refusals divided by the number of persons contacted, i.e. by the number of refusals plus the number of successful or partially successful contacts.

64. **Repeated survey:** A sample survey which is performed more than once with essentially the same questionnaire or schedule but not necessarily with the same sample units.

65. **Representative sample:** In the widest sense, a sample which is representative of a population. Some confusion arises according to whether 'representative' is regarded as meaning 'selected by some process which gives all samples an equal chance of appearing to represent the population'; or, alternatively, whether it means 'typical in respect of certain characteristics, however chosen'. On the whole, it seems best to confine the word 'representative' to samples which turn out to be so, however chosen, rather than apply it to those chosen with the object of being representative.

66. **Sample:** A selected subset of population. A sample may be random or nonrandom and may be representative or nonrepresentative. Several types of sample can be distinguised, including the following:

Cluster sample: Each unit selected is a group of persons (all persons in a city, block, a family, etc.) rather than an individual.

Probability (random) sample: All individuals have a known chance of selection. They may all have an equal chance of being selected, or, if a stratified sampling method is used, the rate at which individuals from several subsets are sampled can be varied so as to produce greater representation of some classes than others. A probability sample is created by assigning an identity (label, number) to all individuals in the "universe" population, e.g. by arranging them in an alphabetical order and numbering in sequence, or simply assigning a number to each or by grouping accordidng to area of residence and numbering the groups. The next step is to select individuals (or groups) for study by a procedure such as use of a table of random numbers (or comparable procedure) to ensure that the chance of selection is known.

Simple random sample: In this elementary kind of sample each person has an equal chance of being selected out of the entire population. One way of carrying out this procedure is to assign each person a number, starting with 1,2,3 and so on. Then numbers are selected at random, preferably from a table of random numbers, and the desired sample size is attained.

Stratified random sample: This involves dividing the population into district subgroups according to some important characteristics such as age or socioeconomic status, and selecting a random sample out of each subgroup. If the proportion of the sample drawn from each of the subgroups, or strata, is the same as the proportion of the total population contained in each stratum (e.g. age group of 40-59 constitutes 20% of the population and 20% of the sample comes from this age stratum), then all strata will be fairly represented with regard to numbers of persons in the sample.

Systematic sample: The procedure of selecting according to some simple, systematized rule, such as all persons whose names begin with specified alphabets born on certain dates, or located at specified points on a master list. A systematic sample may lead to errors that invalidate generalizations. For example, persons' names more often begin with certain letters of the alphabet than with other letters e.g. q, x. A systematic alphabetical sample is therefore likely to be biased.

67. **Sampling:** The process of selecting a number of subjects from all the subjects in a particular group or "universe". Conclusions based on sample results may be attributed only to the population sampled. Any extrapolation to a larger or different population is judgement or a guess and is not part of statistical inference.

68. **Sample design:** The usage is not uniform as regards the precise meaning of this and similar terms like 'sample plan', 'survey design', 'sampling plan' or 'sampling design'. These cover one or more parts constituting the entire planning of a sample survey inclusive of processing, etc. The term 'sampling plan' may be restricted to mean all steps taken in selecting the sample; the term 'sample design' may cover in addition the method of estimation; and 'survey design' may cover also other aspects of the survey, eg. choice and training of the interviewers, tabulation plans, etc. 'Sample design' is sometimes used in a clearly defined sense., with reference to a given frame, as the set of rules or specifications for the drawings of a sample in an unequivocal manner.

69. **Sample size:** The number of sampling units which are to be included in the sample. In the

case of a multi-stage sample this number refers to the number of units at the final stage in the sampling.

**70. Screening:** Screening was defined in 1951 by the US Commission on Chronic Illness as "The presumtive identification of unrecognized disease or defect by the application of tests, examinations or other procedures which can be applied rapidly. Screening test sort out apparently well persons who probably have a disease from the those who probably do not. A screening test is not intended to be diagnostic. Persons with positive or suspicious findings must be referred to the physician for diagnosis and necessary treatment.

Screening is an initial examination only, and positive responders require a second, diagnostic examination. The initiative for screening usually comes from the investigator or the person or agency providing care rather than from a patient with a complaint. Screening is usually concerned with chronic illness and aims to detect disease not yet under medical care.

There are different types of medical screening : mass, multiple or multiphasic, and prescriptive.

Mass screening simply means the screening of whole population.

Multiple or multiphasic screening involves the use of a variety of screening tests on the same occasion.

Prescriptive screening has as its aim the early detection in presumptively health individuals of disese that can be controlled better if detected early in its natural history.

The characteristics of screening test include accuracy, estimates of yield, precision, reproducibility, sensitivity and specificity, and validity.

**71. Sensitivity and specificity:** (of a screening test) Sensitivity is the proportion of truly diseased persons in the screened population who are identified as diseased by the screening test. Sensitivity is a measure of the probability of correctly diagnosing a case, or the probability that any given case will be identified by the test (Syn: true positive rate).

Specificity is the proportion of truly nondiseased persons who are so identfied by the screeing test. It is a measure of the probability of correctly identifying a nondiseased person with a screening test (Syn: true negative rate). The relationships are shown in the following fourfold table, in which the letters a, b, c and d represent the quantities specified below the table.

| Screening test results | True status | | Total |
|---|---|---|---|
| | Diseased | Not diseased | |
| Positive | a | b | a+b |
| Negative | c | d | c+d |
| Total | a+c | b+d | a+b+c+d |

a. Diseased individuals detected by the test (true positives)
b. Nondiseased individuals positive by the test (false positives)
c. Diseased individuals not detectable by the test (false negatives)
d. Nondiseased individuals negative by the test (true negatives)

$$\text{Sensitivity} = \frac{a}{a + b} \qquad \text{Specificity} = \frac{d}{b + d}$$

$$\text{Predictive value (positive test result)} = \frac{a}{a + c}$$

$$\text{Predictive value (negative test results)} = \frac{d}{b + d}$$

72. **Socioeconomic classification:** Arrangement of persons into groups according to such characteristics as prior education, occupation and income. This usually reveals upon analysis a strong correlation with health related characteristics such as avarage length of life and risk of dying from certain specific causes.

73. **Stratification:** The division of a population into parts, known as strata; especially for the purpose of drawing a sample, as assigned proportion of the sample then being selected from each stratum. The process of stratification may be undertaken on a geographical basis, eg. by dividing up the sample area into sub-areas on a map; or by reference to some quality of the population, eg. by dividing the persons in a town into two strata according to sex or into three strata according to whether they belong to upper, middle or lower income groups. The term stratum is sometimes used to denote any division of the population for which a separate estimate is desired, i.e. in the sense of a domain of study. It is also used sometimes to denote any division of the population for which neither separate estimates nor actual separate sample selection is made, eg. the use of strata in stratification after selection when it is used to improve the estimate pertaining to the entire population.

74. **Subsample:** A sample of a sample. It may be selected by the same method as used in selecting the original sample, but need not be so.

75. **Survey:** An investigtation in which information is systematically collected but in which the experimental method is not used. A population survey may be conducted by face-to-face inquiry, by self completed quesionnaries, by telephone, postal service, or in some other way. Each method has its advantages and disadvantages.

76. **Survey instrument:** The interview schedule, questionnaire, medical examination record form etc, used in a survey.

77. **Surveillance of disease:** The continuing scrutiny of all aspects of occurrence and spread of a disease that are pertinent to effective control. Included are the systematic collection and evaluation of (1)morbidity and mortality reports, (2) special reports of field investigations of epidemics and of individual cases, (3) isolation and identification of infectious agents by laboratories, (4) data concerning the availability, use, and untoward effects of vaccines and toxoids, immune globulins, insecticides, and other substances used in control, (5) information regarding immunity levels in segments of the population, and (6) other relevant epidemiologic data. A report summarizing these data should be prepared and distributed to all cooperating persons and others with a need to know the results of the surveillance activities. The procedure applies to all jurisdictional levels of public health from local to international.

78. **Validity, study:** The degree to which the inference drawn from the study, especially generalizations extending beyond the study sample, are warranted when account is taken of the study methods, the representativeness of the study sample, and the nature of the population from which it is drawn. two varieties of study validity are distinguished:

    1. Internal validity: The index and comparison groups are selected and compared in such a manner that the observed differences between them on the dependent variables under study may, apart from sampling error, be attributed only to the hypothesized effect under investigation.

    2. External validity (generalizability): A study is externally valid or generalizable if it can produce unbiased inferences regarding a target population (beyond the subjects in the study). This aspect of validity is only meaningful with regard to a specified external target population. For example, the results of a study conducted using only white male subjects might or might not be generalizable to all human males (the target population consisting of all human males). It is not generalizable to females (the target population consisting of all people). The evaluation of generalizability usually involves much more subject-matter judgement than internal validity.

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*Source: 1. Kendall, M.G. and Buckland, W.R., A Dictionary of Statistical Terms, Third Edition, Hafner Publishing Company, New York, 1972.*

*2. Last, J.M. A Dictionary of Epidemiology, Second Edition, Oxford University Press, New York, 1988.*

Section 13

# Appendices

# National Institute of Mental Health & Neuro Sciences
# Bangalore-560 029

**NEUROEPIDEMIOLOGICAL SURVEY IN URBAN & RURAL AREAS OF BANGALORE**
**(INDIAN COUNCIL OF MEDICAL RESEARCH)**

## Proforma – A
## Sociodemographic Details

1. Serial No. ☐☐☐☐☐

2. Place of survey: ☐
   1. Urban 2. Rural

4. Area Code ☐☐☐

4. Date of Survey ☐☐ ☐☐ ☐☐

5. Name of block / village _____

6. House Number ☐☐☐☐

7. Name of the head of household and address

   (Telephone number if any) ☐☐☐☐☐☐☐

8. Name of the respondent and relation to the head of the household. (If different from HOH) _____

9. Religion ☐
   1. Hindu 3. Christian
   2. Muslim 4. Others, specify

10. Total number of members in the house ☐☐

11. Total approximate income per month ☐☐☐☐☐

12. Period of stay in the locality / village (in months) ☐☐☐

13. Family Composition

| Sl. No. | Name | Age years | Age Months | Sex | Relation to Head of Household | Education | Occupation | Symptoms |
|---|---|---|---|---|---|---|---|---|
| 1. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 2. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 3. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 4. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 5. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 6. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 7. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 8. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 9. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 10. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 11. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 12. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 13. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 14. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |
| 15. | _____ | ☐☐ | ☐☐ | ☐ | _____ | ☐☐ | ☐☐ | ☐ |

Name of the Investigator_____

# National Institute of Mental Health & Neuro Sciences
# Bangalore-560 029

NEUROEPIDEMIOLOGICAL SURVEY IN URBAN & RURAL AREAS OF BANGALORE
(INDIAN COUNCIL OF MEDICAL RESEARCH)

## Proforma – B
## Screening for Individuals 7 year and above

1. Screened number B ☐☐☐☐
2. Serial and Individual number: ☐☐☐☐☐ ☐☐
3. Date of Screening ☐☐ ☐☐ ☐☐
4. Name of the Subject _____

**Have you or any other member of your family suffered from any of the following:**

1. Loss of consciousness ☐
   1. Yes 2. No 3. Don't know
2. Sudden episode of loss of contact with the surroundings ☐
   1. Yes 2. No 3. Don't know
3. Shaking of head, arms or legs which could not be controlled ☐
   1. Yes 2. No 3. Don't know
4. Is the speech abnormal? ☐
   1. Yes 2. No 3. Don't know
5. Has the face ever been paralysed with deviation of mouth to one side ☐
   1. Yes 2. No 3. Don't know

[P.T.O.

6. Have the arms or legs ever been paralysed? ☐
   1. Yes 2. No 3. Don't know

7. Is there any difficulty in walking properly ☐
   (to exclude individuals with pain or swelling of joints of lower limbs)
   1. Yes 2. No 3. Don't know

8. Has the sensation over the face, arms and legs ever been lost or abnormal ☐
   1. Yes 2. No 3. Don't know

9. Has the memory deteriorated within the last five years ☐
   (applicable to subjects above 30 years of age)
   1. Yes 2. No 3. Don't know

10. Has drooping of eye lids ever occured? ☐
    (a) Temporary for few hours or (b) Permanent
    1. Yes 2. No 3. Don't know

11. Episodes of severe pain in the face ☐
    1. Yes 2. No 3. Don't know

12. Headache: ☐
    1. Yes 2. No 3. Don't know

If yes ☐

12.1. Unilateral ☐

12.2. Associated with flashes of light or circles ☐

12.3. Associated with vomiting ☐

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Name of Investigator

# National Institute of Mental Health & Neuro Sciences
# Bangalore-560 029

NEUROEPIDEMIOLOGICAL SURVEY IN URBAN & RURAL AREAS OF BANGALORE
(INDIAN COUNCIL OF MEDICAL RESEARCH)

## Proforma – C
## Screening for Individuals below 7 years of age

1. Screened number ☐☐☐☐☐
2. Serial and Individual number: ☐☐☐☐☐ ☐☐
3. Date of Screening ☐☐ ☐☐ ☐☐
4. Name of the Child _____
5. Name of the informant and relationship _____

**Has your child suffered from any of the following:**

1. Has the child ever lost consciousness ☐
   1. Yes 2. No 3. Don't know
2. Does the child have episodes of blank look and unawareness of surroundings ☐
   1. Yes 2. No 3. Don't know
3. Did the child ever have convulsions preceded by fever ☐
   (for children under 6 years of age only)
   1. Yes 2. No 3. Don't know
4. Did the child ever have shaking of arms or legs without control ☐
   1. Yes 2. No 3. Don't know
5. Did the child ever have deviation of mouth to one side? ☐
   1. Yes 2. No 3. Don't know

[P.T.O.

6. Did the child ever have paralysis of arms or legs? ☐
   1. Yes 2. No 3. Don't know

7. Did the child ever have drooping of eye lids for few hours or longer? ☐
   1. Yes 2. No 3. Don't know

8. Did the child hold the neck at 4 months of age ☐
   1. Yes 2. No 3. Don't know

9. Did the child sit at 6 months of age ☐
   1. Yes 2. No 3. Don't know

10. Did the child stand up at 1 year of age ☐
    1. Yes 2. No 3. Don't know

11. Did the child walk at 2 years of age ☐
    1. Yes 2. No 3. Don't know

12. Did the child run at 3 years of age ☐
    1. Yes 2. No 3. Don't know

13. Did the child start speaking few words at 18 months ☐
    1. Yes 2. No 3. Don't know

14. Can the child speak normally (applicable for children over 3 years of age) ☐
    1. Yes 2. No 3. Don't know

15. Is the child of normal intelligence (applicable to children over 3 years of age) ☐
    1. Yes 2. No 3. Don't know

Name of Investigator:_____

# National Institute of Mental Health & Neuro Sciences
# Bangalore-560 029

NEUROEPIDEMIOLOGICAL SURVEY IN URBAN & RURAL AREAS OF BANGALORE
(INDIAN COUNCIL OF MEDICAL RESEARCH)

## Proforma – D
## Clinical Evaluation

1. Screened Number 1. B 2. C ☐☐☐☐☐

2. Serial and Individual No. ☐☐☐☐☐ ☐☐

3. Clinical examination No. ☐☐ ☐☐

4. Date of examination ☐☐ ☐☐ ☐☐

5. Name of the subject _____

6. Screened positive on items

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
| 6 | 7 | 8 | 9 | 10 |
| 11 | 12 | 13 | 14 | 15 |

7. Previous Treatment ☐
   1. Treated
   2. Untreated

8. If treated, by ☐
   1. Internist
   2. Paediatrician
   3. Practitioner
   4. Neurologist
   5. Other Specialists—Specify,. . . . . .
   6. Traditional healer—Specify,. . . . . .

9. Place of Hospitalisation ☐
   1. NIMHANS
   2. Government Hospital
   3. Private Hospital
   4. Nursing Home
   5. District Hospital
   6. Primary Health Centre

[P.T.O.

10. If seen at NIMHANS ☐☐☐
    1. Neurology
    2. Neurosurgery
    3. Psychiatry

11. Screening confirmation on

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
| 6 | 7 | 8 | 9 | 10 |
| 11 | 12 | 13 | 14 | 15 |

12. Duration of illness

| Years | Months |
|---|---|
| ☐☐ | ☐☐ |

13. Diagnosis ☐
    1. Neurological
    2. Nil Neurological

14. Clinical diagnosis
    a) ☐☐☐
    b) ☐☐☐
    c) ☐☐☐

Name of the Doctor_____

# National Institute of Mental Health & Neuro Sciences
# Bangalore-560 029

NEUROEPIDEMIOLOGICAL SURVEY IN URBAN & RURAL AREAS OF BANGALORE
(INDIAN COUNCIL OF MEDICAL RESEARCH)

## Proforma – E
## Neurological Assessment

1. Serial and Individual No. ☐☐☐☐☐ ☐☐

2. Name of the subject _____

3. Brief Complaints

4. Brief History

5. Family history of similar or other neurological illness ☐

   A) Present 2) Absent

6. General Examination:

[P.T.O.

7. Neurological Examination

Higher mental functions

Speech

Fundus

Cranial Nerves

Motor System

Sensory System

Reflexes

Gait

Co-ordination

Any others

Name of the Doctor_____

# National Institute of Mental Health & Neuro Sciences Bangalore-560 029

## NEUROEPIDEMIOLOGICAL SURVEY IN URBAN & RURAL AREAS OF BANGALORE (INDIAN COUNCIL OF MEDICAL RESEARCH)

### CODING FOR EDUCATION AND OCCUPATION

**Educational Status:**

1. Illiterate
2. Primary
3. Secondary
4. High School
5. Junior/Pre University
6. Vocational
7. Graduate
8. Post Graduate
9. Professional
10. Not applicable
11. Not known

**Coding for Occupation:**

01. Architects, Engineers & Surveyors
02. Chemists, Physicists, Geologists & Other Physical Scientists
03. Biologists, Veterinarians & Related Scientists
04. Doctors
05. Nurses, Pharamacists & other health technicians
06. Teachers
07. Jurist
08. Special Scientists
09. Artists, Writers & Related workers
10. Draughtman, Science & Engineering technicians
11. Administrators & Executive Officials
12. Directors and Managers
13. Clerical and related workers
14. Sales workers
15. Agricultural Owners
16. Agricultural labourers
17. Fisherman & Sea workers
18. Miners, Quarrymen & Related workers (Construction Workers)
19. Transport and Communication sector workers
20. Drivers of transport vehicles
21. Related workers in transport sector
22. Spinners, Weavers and Cutters
23. Tailors, Cutters and related workers
24. Leather Industry workers
25. Toolmakers, Machinists, Plumbers, Welders & related workers
26. Electricians & related workers
27. Carpentry, painting, press workers & potters
28. Labourers not classified any where
29. Policeman, fire fighters, guards and related workers
30. Service, sports and recreation workers
31. Unemployed
32. Students
33. House wives
34. Business people
35. Casual labourer
36. Retired people
37. Not applicable
38. Not known
39. Information not available
40. Others, specify

# National Institute of Mental Health & Neuro Sciences Bangalore-560 029

## NEUROEPIDEMIOLOGICAL SURVEY IN URBAN & RURAL AREAS OF BANGALORE (INDIAN COUNCIL OF MEDICAL RESEARCH)

### MONITORING AND SURVEILLANCE SHEET

1. Serial number.
2. Area / Lane.
3. Enumeration Block number.
4. House number.
5. Head of the Household.
6. Survey : Completed / Rejected.
7. Total number of houses visited.
8. Total number of houses where survey is completed.
9. Total number of houses where survey has to be completed
10. Reasons for noncompletion :
    a.
    b.
    c.
    d.
11. Total number of adults
12. Total number of adults screened.
13. Total number of adults to be screened
14. Total number of children
15. Total number of children screened.
16. Total number of children to be screened.
17. Total number of screened positives
18. Total number of clinical examination completed.
19. Total number of clinical examination to be completed.
20. Reasons for non-completion.

# National Institute of Mental Health & Neuro Sciences Bangalore-560 029

## NEUROEPIDEMIOLOGICAL SURVEY IN URBAN & RURAL AREAS OF BANGALORE (INDIAN COUNCIL OF MEDICAL RESEARCH)

### OPERATIONAL DEFINITION OF NEUROLOGICAL DISORDERS

1. **Active epilepsy :**

   a) If previously untreated, the subject must have had at least two afebrile seizures, the last of which must have occured within 2 years of the reference date.

   b) If under treatment, the subject must have had at least two afebrile seizures in the preceeding 5 years and at least one afebrile seizure in the preceeding 2 years.

2. **Generalised tonic - clonic seizures :**

   Loss of consciousness, followed by tonic-clonic movements involving all four limbs or remaining unilateral.

3. **Simple partial seizures :**

   Seizures commencing with focal motor/sensory symptoms with or without progression or generalisation.

4. **Complex partial seizures :**

   Seizures with complex symptoms such as psychic/special sensory symptoms with or without automatisms, impaired sensorium, generalisation

5. **Absence seizures :**

   Transient impairment of consciousness which may be associated with automatisms. The onset and cessation of the attack is abrupt without postictal phenomena. Usually numerous attacks occur in a day.

6. **Myoclonic seizures :**

   Sudden single/multiple jerky movements of a part or an entire limb or entire body. May be mild to severe resulting in fall.

7. **Febrile convulsions :**

   Convulsions associated with fever in children under the age of 5 but without evidence of intracranial infection.

8. **Syncope :**

   Abrupt loss of consciousness of brief duration with spontaneous and complete recovery.

9. **Vascular headache (Migraine) :**

   Paroxysmal severe headache chiefly on one side associated with any of the following (a) visual disturbances (b) nausea and (c) vomiting.

10. **Cerebrovascular disorders :**

    Sudden or rapid onset of focal neurological signs, due to focal brain dysfunction lasting longer than 24 hours and of presumed vascular origin.

11. **Mental retardation :**

    Symptom complex of incomplete or insufficient development of mental capacities and associated behavioural abnormalities.

12. **Cerebral palsy :**

    A heterogenous group of disorders with damage to the nervous system, in utero, at or immediately after birth and absence of progressive disorders, with clinical features of disorder of movement or posture.

13. **Dementia :**

Clinical syndrome comprising of failing memory and loss of other intellectual functions due to progressive disease of the brain.
(Depression and other forms of functional psychosis to be excluded)

14. **Parkinson's disease :**

Presence of at least three of the following signs : (i) tremors at rest (ii) rigidity (iii) akinesia and (iv) postural instability. Essential tremors and drug induced syndromes to be exclued.

15. **Tremors :**

Regular rhythmic oscillation of part of the body around a fixed point.

16. **Essential tremor :**

Tremors of hands or head or both: should have been present for many years or have positive family history of the same disorder.

17. **Chorea :**

Involuntary irregular arrhythmic rapid jerky movement.

18. **Dystonia :**

Persistent attitude or posture affecting trunk and proximal limb muscles.

19. **Athetosis :**

Continuous slow sinuous movement usually involving distal parts of the limbs.

20. **Tics :**

Habitual voluntary movements which can be inhibited by effort.

21. **Multiple sclerosis :**

(a) Involvement of two or more separate areas in the central nervous system (b) predominantly white matter involvement, (c) dissemination in time between two or more, with each episodes of one month or more. Each episode lasting atleast for 24 hours and (d) past history of remission.

22. **Peripheral nerve disorder :**

Parasthesia, sensory impariment, weakness, wasting of muscles and hyporeflexia, occurring alone or in various combinations, attributable to altered function of lower motor, sensory neurons and their processes.

# National Institute of Mental Health & Neuro Sciences Bangalore-560 029

**NEUROEPIDEMIOLOGICAL SURVEY IN URBAN & RURAL AREAS OF BANGALORE (INDIAN COUNCIL OF MEDICAL RESEARCH)**

## DIAGNOSTIC CODING LIST

**1. Epilepsy**

- 1.1 Generalised tonic clonic epilepsy
- 1.2 Absence
- 1.3 Myoclonic epilepsy
- 1.4 Simple Partial Seizures (Focal motor/Sensory with/without generalisation)
- 1.5 Complex Partial Seizures (with or without generalisation)
- 1.6 Others, specify (Pseudoseizures, multifocal, akinetic)

**2. Febrile convulsions**

**3. Syncope**

**4. Headache**

- 4.1 Classical migraine (with aura)
- 4.2 Common migraine (without aura)
- 4.3 Complicated migraine
- 4.4 Cluster headache (Horton's headache)
- 4.5 Tension headache
- 4.6 Psychogenic headache (underlying psychiatric disorder)
- 4.7 Hypertension
- 4.8 Sinusitis
- 4.9 Post traumatic
- 4.10 Raised intracranial tension
- 4.11 Others, specify

**5. Cerebrovascular disorder**

- 5.1 *Ischemia*
  - 5.1.1 Transient Ischemic Attacks (TIA) (Deficit resolves within 24-48 Hours)
  - 5.1.2 Reversible Ischemic Neurological Deficit (RIND) (Deficit resolves from 2-7 days)
  - 5.1.3 Completed Stroke
- 5.2 *Haemorrhage*
  - 5.2.1 Cerebral Haemorrhage
  - 5.2.2 Primary Subarachnoid haemorrhage
- 5.3 *Cerebral Venous Thrombosis*
  - 5.3.1 Puerperal
  - 5.3.2 Non puerperal
- 5.4 Unclassified

**6. Mental Retardation** (including cerebral palsy, progressive cerebral degeneration)

**7. Dementia**

- 7.1 Multi-infarct
- 7.2 Degenerative disorders
- 7.3 Others (infective - syphilis, cysticercosis, nutritional deficiency)

8. **Parkinson's Disease**
   - 8.1 Idiopathic
   - 8.2 Secondary (Drug induced, postencephalitic, toxic)

9. **Tremors** (Exclude Parkinson's disease, Cerebellar disorders)
   - 9.1 Essential Tremors
   - 9.2 Others, (Drug induced, senile, anxiety)

10. **Other involuntary movements** (Exclude Parkinson's disease and Tremors)
   - 10.1 Chorea
   - 10.2 Dystonia (Include blepharospasm, orofacial dyskinesis, torticollis, writer's cramp)
   - 10.3 Athetosis
   - 10.4 Mixed
   - 10.5 Others, (Hemiballismus, tics, miscellaneous)

11. **Cerebellar disorders**
   - 11.1 Drug induced (phenytoin, carbamezapine)
   - 11.2 Inherited ataxia (Friedreich's, PCA, other spino cerebellar degeneration)

12. **Demyelinating disorders of CNS** (Multiple sclerosis, post-vaccinal, post-infective encephalomyelitis)

13. **Speech disorders**
   - 13.1 Due to neurological disorders (Aphasia, dysarthria)
   - 13.2 Non neurological (Stammering, lalling speech)

14. **Cranial nerve disorders** (excluding facial nerve disorders)

15. **Facial nerve disorder**
   - 15.1 Bell's palsy
   - 15.2 Hemifacial spasm

16. **Spinal cord disorders** (Myelopathy, radioculomyelopathy)
   - 16.1 Compressive
   - 16.2 Non compressive

17. **Anterior horn cell disorders**
   - 17.1 Motor neurone disease (Classical MND, Madras type, Monomelic amyotrophy)
   - 17.2 Spinal muscular atrophy
   - 17.3 Poliomyelitis sequelae
   - 17.4 Others, specify

18. **Peripheral nerve disorders**
   - 18.1 Radiculopathy (includes disc prolapse)
   - 18.2 Plexus lesions
   - 18.3 Peripheral neuropathy (Mononeuropathy, mononeuritis multiplex, peripheral neuropathy)
   - 18.4 Neuralgias (Herpes zoster, others)

19. **Disorders of neuromuscular junction** (Myasthenia, any others)

20. **Disorders of muscle** (Muscular dystrophy, congenital and acquired myopathies)

21. **Post-traumatic sequale** (exclude epilepsy)

22. **Post-encephalitic/Post meningitic sequelae**

23. **Intracranial lesions**

24. **Neurological disorder not otherwise specified**

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## About the authors

Dr. M. Gourie-Devi, MD; DM(Neuro), FAMS, Professor and Head of the department of Neurology, National Institute of Mental Health and Neuro Sciences, Bangalore, has been interested in the field of neuroepidemiology for over a decade and has made significant contributions in the field with special reference to development of protocol for detection of neurological disorders in the community, prevalence rates of neurological disorders and methodological issues for conducting neuroepidemiologic survey in developing country. Her other research interests are neuromuscular diseases, clinical neurophysiology and neuroinfections. These varied interests of hers have helped in interlinking neuroepidemiology to these clinical problems. She has authored 90 scientific papers and chapters in books. She has also edited a book on motor neurone disease.

G. Gururaj, MBBS, MD (Community Medicine), Additional Professor of Epidemiology, National Institute of Mental Health and Neuro Sciences, Bangalore, received advanced training in epidemiology in USA through a WHO fellowship in 1990 and has wide experience in conducting community based studies on various communicable and noncommunicable diseases and organising services for individuals in rural and urban areas. Current research interests include epidemiology and prevention of neurological diseases, traumatic injuries including head injuries and mental health problems. He has published 25 papers on different topics from an epidemiological and public health point of view.

P. Satishchandra, MBBS, DM(Neuro), MAMS, Additional Professor of Neurology, National Institute of Mental Health and Neuro Sciences, Bangalore, was awarded an International Neurosciences Fellowship and was a visiting associate at the neuroepidemiology branch of National Institute of Health (NIH), Bethesda, USA, where he received training in neuroepidemiology. He has 50 scientific publications dealing with epilepsy, neuroepidemiology, neuroinfections and electrophysiology in the areas of his interest.